Nursing conceptualizations of research and practice

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Despite the fact that computer use in health care and nursing is burgeoning, nurses often find that they have inadequate tools with which to manage information about complex phenomena. Family is one such complex phenomenon of interest to nurses. Commonly-used computer tools for managing information about families may not be congruent with the ways that individuals define their families and may not be consistent with nursing conceptualization of families as dynamic groups not necessarily limited to biologically related individuals. Building nursing knowledge on incongruent conceptualizations will result in inaccurate knowledge. Communication and collaboration between nurse researchers, clinicians, and nursing informatics researchers are needed in order to produce tools that are consistent with nursing conceptualization and that will support nursing research and practice.

The use of computers in health care and nursing is growing, as is the amount of information available and necessary for nursing research and practice. The increasing use of electronic health records (EHRs) and the proliferating availability of electronic health information indicate that the use of and reliance on computers in health care will continue to expand. Nursing has a valuable opportunity and an important responsibility to ensure that information is managed in computers in ways supportive of nursing research and practice.

The purpose of this article is to illustrate the pressing need for computational tools that are consistent with nursing conceptualization. By reviewing how nursing knowledge is captured in computers, exploring the complex concept of family, and comparing and contrasting the concept of family with computational tools commonly used within health care to manage information about families, we aim to depict the chasm between nursing conceptualization about family and the tools currently available to help nurses manage information about family in research and practice. We will critically examine how congruence or incongruence between the conceptualization and representation of complex concepts such as family can impact nurse researchers and clinicians. We will conclude by envisioning how computer tools based on nursing conceptualization might be developed, how they could benefit nurses and persons receiving nursing care, and what actions nurses can take to ensure that computer tools that support nursing will exist.

CAPTURING NURSING KNOWLEDGE IN COMPUTER SYSTEMS

Every computer tool or application is the result of programs, rules, and algorithms. Although nurses may not commonly think about the computer programs behind the tools they use, these rules and algorithms transform and process data into usable information for nursing research and practice and, therefore, are directly responsible for how well a tool works for nursing purposes. Nursing informatics researchers are interested in how nursing data, information, and knowledge are entered, processed, stored, and applied in computer systems. According to the *Scope and Standards of Nursing Informatics Practice*: "Nursing informatics is a specialty that integrates nursing science, computer science, and information science to manage and communicate data, information, and knowledge in nursing practice. Nursing informatics facilitates the integration of data, information, and knowledge to support patients, nurses, and other providers in their decision-making in all roles and settings. This support is accomplished through the use of information structures, information processes, and information technology."[1]

Although the terms *data, information*, and *knowledge* are often used interchangeably in informal discussion, nursing informatics researchers recognize these terms as related but distinct as described in a seminal publication by Graves and Corcoran.[2] Data are discrete entities which have an objective value but are not interpreted.[2] The integer "98" or the character string "V132" are examples of data. Information results from multiple data being organized and interpreted; computer information systems create information from data.[2] For example, if a clinical information system generated a chart depicting an individual's pulse rate

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over a 5-day period, this chart could include the datum 98, now interpreted as the pulse rate on day 3.

Knowledge is built by processing or transforming information such that new relationships are identified, generating decisions and discoveries.[2] Transformation of information to knowledge is used for discovery in nursing research and may support nursing practice through clinical nursing decision support systems. Knowledge discovery in databases is one methodology by which nurse researchers use the transformation of information into knowledge to discover new relationships and build nursing knowledge.

Data and information in computers may be entered, managed, and displayed to the user in multiple ways. *Representation* refers to the manner in which information is entered, stored, and processed within computers and displayed to users—literally, how the information is represented within and by the computer system. A representation embodies a commitment about which data can be entered, how they will be acted upon by the computer system, and how they will be displayed. Correspondingly, that which is not entered and/or not displayed is assumed to be unimportant or irrelevant. This implicit but important assumption underscores how imperative it is for the discipline of nursing to ensure that phenomena of importance to nurses are represented in computer systems in ways that are consistent with nursing knowledge and conceptualization to prevent omission, distortion, or trivialization of important information.

Creating and evaluating ways to electronically represent data, information, and knowledge of interest to nurses is an important focus of nursing informatics research. For example, nursing informatics researchers have made considerable progress in developing standardized terminologies to represent nursing assessments and nursing interventions in computer systems.[3–6] Standardized terminologies and information structures enable computers to manipulate and integrate nursing information[7] and may be useful for activities such as guiding data collection, integrating nursing research findings, and supporting documentation and analysis of nurses' knowledge in practice.

FAMILY: AN EXAMPLE OF AN IMPORTANT NURSING CONCEPT

The family history is receiving renewed attention as a vital source of information for research and clinical assessment in nursing and other health professions.[8,9] Because it reflects genetic, environmental, and behavioral factors that are often shared within families and result in familial patterns of disease, the family history is an invaluable genomic screening tool for assessing individual and family risk.[10,11] Indeed, the ability to collect and analyze a 3-generation family history has been identified as an essential competency for registered nurses.[12]

However, the emphasis on using family history for individual and family risk assessment is but one reason that nurses are interested in families. Nurses have appreciation for the influence of family on individual health; consider families, as well as individuals, as clients of nursing care; and recognize that a family may be a valuable resource offering protection, social support, and care to its members. Nursing authors have also stressed the importance of providing genomic care within the context of family.[13–15]

A challenging and complex concept, most people have an idea about what a family is, but few find the term easy to define. Nevertheless, examination of nursing literature demonstrates evidence of a shared conceptualization of family. Common elements include the family as: (1) a dynamic group of 2 or more; (2) self-defined; and (3) characterized by a special association between members, including shared values, shared goals, and/or interdependence on one another.[16–20]

The American Nurses Association *Code of Ethics for Nurses*[21] explicates the goals, values, and obligations of professional nursing. Respect for individual differences and values, as elucidated in the code, is fundamental to professional nursing. Nursing's broad, inclusive conceptualization of family reflects this essential value and acknowledges that contemporary families are diverse and dynamic. Families include individuals who may or may not be biologically or legally related but who identify themselves as family. Narrowly defining the family as a biological unit could mean that information that may influence individual and family health may be overlooked for family members without a biological relationship.

Whereas a biological or legal relationship between adults and their children may be considered essential in traditional definitions of family, U.S. census data illustrate the diversity and changes in families occurring over the past decade, in which only slightly more than half (52%) of family households were married couple households, and increased numbers of households were comprised of a mother and her children, a father and his children, unmarried partners, and multigenerational families.[22]

In fact, the nuclear family, consisting of 2 married parents and their children, currently accounts for only a quarter of American households.[23] Single parent families, blended families, adoptive and foster families, unmarried partners with and without children, adult children living with their parents, and grandparents rearing grandchildren make up a growing number of contemporary American families.[24–27] Finally, families may include fictive kin—people who are not biologically or legally related but are considered family and provide emotional, social, or financial support.[28,29] These transformations underscore the need for a robust tool that readily accommodates the diversity of contemporary

Table 1. Select Electronic Tools for Representing Information About Families Available Online

Name	URL	Description
My Family Health Portrait	www.hhs.gov/familyhistory/	Free consumer application for creating pedigree and chart representations of family history
GenoPro	www.genopro.com/	Commercial application for drawing genograms
Genoware	www.genogram.org	Commercial application for drawing genograms
SmartDraw	www.smartdraw.com	Commercial application that supports drawing genograms and ecomaps

families to support professional nursing research and practice.

COMPUTATIONAL APPROACHES TO MANAGING PERSONAL AND FAMILY INFORMATION

Information technology will play an increasingly important and even transformative role in healthcare in the 21st century.[30] Agencies within the US Department of Health and Human Services have collaborated to launch the Family History Initiative, a public health campaign designed to increase awareness of the importance of family history and to provide tools enabling consumers to organize and maintain their family history information.[31] Efforts are under way to develop the National Health Information Infrastructure (NHII), with the aim of delivering both patient-specific information and decision-support based on the latest scientific findings and guidelines to nurses and other healthcare providers at the point of care.[32–34] And a recent white paper authored by the American Medical Informatics Association Nursing Informatics Working Group (AMIA NIWG) identified the importance of nurses' involvement in the development of electronic personal health records that will enable consumers to enter their own health information in a format that can be shared with providers to enhance patient-centered care and improve healthcare quality.[35] These efforts foreshadow an exciting future in which consumers may be able to enter complete family information into a personal health record and electronically share this information with their healthcare providers. These efforts also afford the nursing discipline an important opportunity to become involved in developing electronic tools for managing family information and ensuring that family in healthcare is defined in such a way that does not exclude nontraditional families.

At this time, computer applications for managing family history information are primarily limited to storing and displaying information about the biological family. For example, the online tool *My Family Health Portrait* (https://familyhistory.hhs.gov/), a product of the Family History Initiative, enables the consumer to enter data about his or her biological family members,

store a family history file on his or her personal computer, and print the family history file to review with a clinician. In clinical settings, EHRs typically contain similar simple tools, enabling nurses and other clinicians to enter and store information about their patients' biological family history.

Charts and pedigrees are commonly used representations of information about the biological family. A chart generally includes a list of family members on the vertical axis and a list of diseases on the horizontal axis, with the body of the chart indicating whether each family member has a history of each disease. A pedigree, sometimes called a family tree, is a graphical representation of family history in which circles and squares represent female and male individuals and connecting lines between the shapes indicate relationships. Pertinent health information about individual family members, such as diagnoses or behaviors, may be recorded in text on the pedigree or represented symbolically. This graphical format facilitates visual analysis.

Genograms and ecomaps are 2 additional types of graphical representations of family information sometimes used by nurses. A genogram looks similar to a pedigree, but includes information different from that found in a pedigree, such as relationship qualities, life events, and functional patterns of the family.[36] In contrast, an ecomap is a visual representation that depicts relationships between the family and other social systems, such as school, workplace, extended family, and religious organizations. Applications for creating genograms and ecomaps are not typically part of EHRs, but computer tools for drawing both are commercially available (see Table 1).

We will use an example to illustrate some inherent limitations and potential ramifications associated with the application of these widely used representations of family to nontraditional families. "Lia" is a fictional healthy 45-year-old woman whose family history is remarkable for heart disease. Lia's biological father and paternal uncle were diagnosed with coronary artery disease in their late 40s. Her paternal grandmother was diagnosed with coronary artery disease in her 60s and

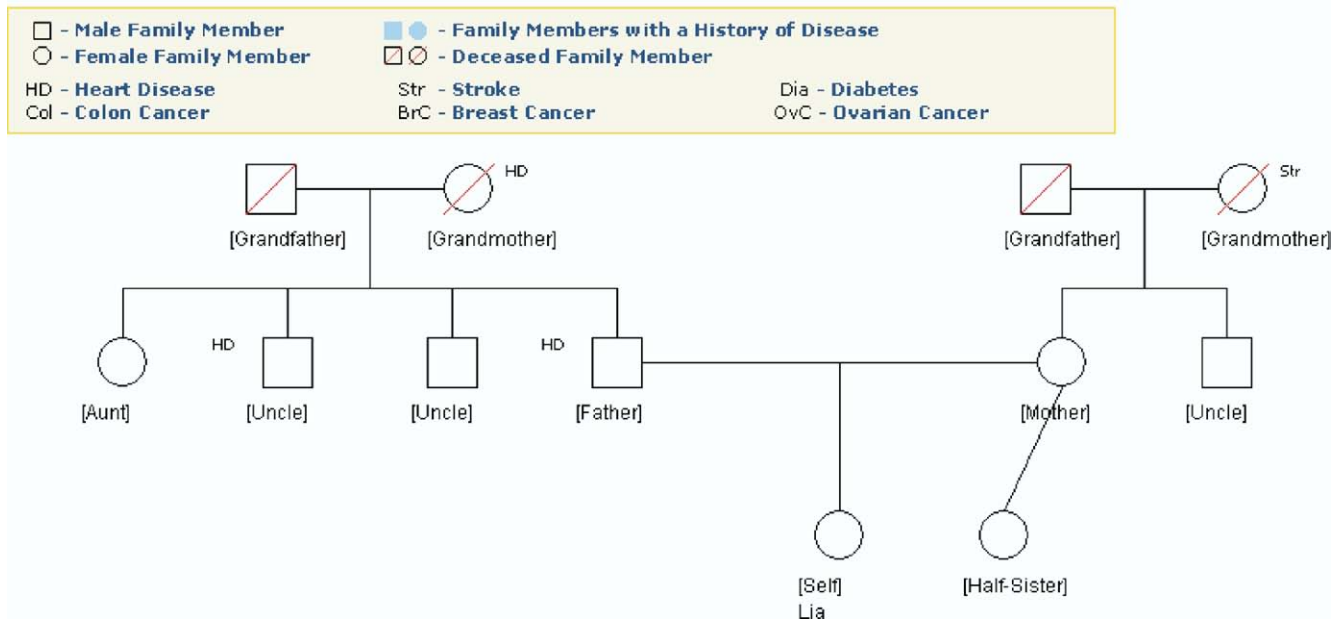My Family Health Portrait - Drawing Report
Lia - March 27, 2008

Figure 1. Pedigree created in My Family Health Portrait.

died at age 71 due to myocardial infarction. This familial pattern of heart disease indicates that Lia's paternal family may share genetic and/or environmental factors associated with heart disease. This family history information is illustrated in the pedigree shown in Figure 1 and the chart shown in Figure 2, both of which were generated using *My Family Health Portrait.* The purpose of this example is not to critique *My Family Health Portrait* specifically, as it may be a useful tool for documenting one's biological family health history. Rather, the purpose is to demonstrate that information about nontraditional families may be inaccurate or missing from common representations of family history like these, which are typical of family history representations used in healthcare.

Lia's parents divorced when she was a child, and she was reared by her mother and stepfather. Her stepfather has been obese since young adulthood and is a cigarette smoker, but is otherwise healthy. Her 2 stepsisters also smoke and are overweight. This information is missing from the pedigree and chart representations of Lia's family history, but is important to the nurse who is assessing Lia's risk for heart disease and working with Lia to personalize a prevention strategy. Although Lia does not share genetic factors with her stepfamily, the pattern of smoking and obesity in her stepfamily indicate that Lia may have been exposed to environmental risk factors for cardiovascular disease, such as second-hand smoke and high calorie, high-fat diet.

Lia's spouse is healthy and active and walks a 3-mile route several times a week with Lia. He is also missing

My Family Health Portrait - Chart Report
Lia - March 27, 2008

Use this in consultation with your healthcare professional.
It can be a valuable tool for discussion, risk assessment, and medical advice.

My Stats: Age: 45

	Still Living?	Heart Disease	Stroke	Diabetes	Colon Cancer	Breast Cancer	Ovarian Cancer	Additional Diseases
Lia [Me]	Yes	No	No	No	No	No	No	
[Mother]	Yes	No	No	No	No	No	No	
[Mother's Mother]	No Stroke at 84	No	Yes, 60 and older	No	No	No	No	
[Mother's Father]	No	No	No	No	No	No	N/A	
[Father]	Yes	Yes, At age 40-49	No	No	No	No	N/A	
[Father's Mother]	No Myocardial Infarction at 71	Yes, 60 and older	No	No	No	No	No	
[Father's Father]	No	No	No	No	No	No	N/A	
[Half Sister]	Yes	No	No	No	No	No	No	
[Father's Sister]	Yes	No	No	No	No	No	No	
[Father's Brother]	Yes	Yes, At age 40-49	No	No	No	No	N/A	
[Father's Brother]	Yes	No	No	No	No	No	N/A	
[Mother's Brother]	Yes	No	No	No	No	No	N/A	

Figure 2. Chart created in My Family Health Portrait.

from the biological family history representations, but information about him is valuable to Lia's nurse because he and Lia share important environmental factors related to health and disease. The healthy and supportive influence of her spouse may mitigate her risk for heart disease. Lia's spouse also may be an important source of support if Lia and the nurse decide that additional lifestyle modifications are needed.

As this example demonstrates, traditional pedigrees may be useful and appropriate representations for biologically related kin, but important information about other family members, such as Lia's stepfamily and spouse, are not available to nurses working with these representations in practice and research. The absence of information about these other family members may have important ramifications for nurse researchers or clinicians working with Lia. For example, because Lia's stepfamily does not appear in the pedigree, the nurse may fail to address environmental risk factors to which Lia may have been exposed or share (secondhand smoke, high calorie/high fat diet). Because Lia's spouse does not appear in the representations, the nurse may fail to capitalize on an important healthy influence and source of support for Lia.

The use of a genogram would enable Lia's nurse to incorporate information about non-biologically related family members and relationship qualities, but would not include the depth of health information found in a pedigree. In the example case of Lia, her stepparent, stepsiblings, and spouse could be depicted, along with information about their relationships with Lia, but the genogram used in isolation would likely omit details of the health history. The use of an ecomap would enable the nurse to document interactions between Lia's family and social systems but would not include detail about family members' health and relationships.

In practice, nurses may use all 3 tools (pedigrees, genograms, and ecomaps) to document family history information about one patient.[37] However, all 3 of these tools are visual aids for human analysis, placing the burden of interpretation and integration of the information on the nurse. Olsen and colleagues[10] asserted that nurses in practice integrate concepts from these 3 tools to develop a holistic understanding of the family. The authors suggested that a computer tool is needed to support nurses in this cognitively demanding task. Such a tool might be a positive step toward a representation of family that embraces nursing conceptualization of family.

Although nurse researchers and clinicians are accustomed to adding in extraneous but important information that does not fit into a pedigree or chart when documenting on paper, this is not practical with electronic versions of family history tools. Although adding a narrative note to a research database or EHR describing step-relatives, spouses, or other family information may be possible, information recorded in the narrative note will not be interpreted, analyzed, and processed by the computer in the same manner as family history information entered in the intended location, diminishing the ability of the information system to integrate and use the information for decision support and knowledge development. Additionally, other users are less likely to find information when it is placed in an unexpected site.

In considering the limitations of traditional family history representations applied to diverse families, it is important to recall that, when a representation is selected to manage and process information about a phenomenon within a computer system, a commitment is made regarding how that phenomenon is defined. In the case of family, if representations are limited to the biological family, then there is implicit acceptance of the definition of family as a biologically related group of individuals and implicit rejection of broader, more diverse definitions of family. This is in contrast to the nursing conceptualization of family as a dynamic and self-defined group whose members may or may not be biologically related, and inaccurate knowledge may result because important information about some family members is omitted. For this reason, it is imperative that a more inclusive conceptualization of family be used in these commitments.

Inaccurate knowledge may occur not only because representations omit family members but also because a particular family history representation may contain information that is not relevant in given situations in which nurses use information about families. Examples include an adopted person whose pedigree contains his biological family members, although he might not consider them his family, or a child reared by grandparents whose pedigree includes one or both of his parents despite their not assuming a parenting role in his family. Information about these family members is important in certain contexts, as when analyzing genetic risk factors, but information about these family members is less important or even confounding in other contexts. For example, if the child being reared by his grandparents is an adolescent newly diagnosed with diabetes, the incorrect assumption could be made that a parent is involved in meal preparation when in fact the grandparents who live and eat with the adolescent are more likely to be involved with meal preparation. Although such information can be clarified in a clinical setting, additional time is required, and misunderstandings and errors that may impact the relationship between the nurse and the individual and/or family are possible. In a research setting, clarification may be much more difficult to accomplish.

Nursing research has also been constrained by inadequate family history tools and would benefit from the introduction of family history tools based on the more inclusive nursing conceptualization of family. The lack of tools that represent real families has left researchers

relying on tools that represent only the biological family. For example, pedigree tools have been used to collect data about biological family members, and nursing researchers have analyzed those data to explore children's exposure to behavioral, environmental, and genetic risk factors.[38,39] As previously described, although these tools are appropriate for examining genetic risk, they may be inappropriate for analyzing the behavioral and environmental factors that family members share, because it is not clear what role biological family members play in the family or what information is missing about other family members who do have environmental factors and behaviors in common. Given the diversity of contemporary families, making conclusions about shared behavioral and environmental risk factors in families based on representations of the biological family is error-prone. Recent findings about the spread of obesity within social networks emphasized the important role of non-biologically related individuals in the development of environmental and behavioral risk factors.[40] Family history tools based on nursing conceptualization of family would support nurse researchers in collecting and analyzing data about behavioral and environmental factors shared by members of diverse families in concert with the genetic factors shared by biological family members.

Nurse researchers and clinicians need more robust computational tools to support collection and analysis of complex family information. Familiar tools that served in the past are no longer adequate as genomic knowledge expands, families become increasingly diverse, and our need to synthesize this information into nursing knowledge becomes pressing. Nurses now have a unique opportunity to create tools that embrace the diversity seen in contemporary families to support genomic nursing research and enhance nursing practice.

ENVISIONING A NURSING REPRESENTATION OF FAMILY

The ideal computational tool to represent family for nursing research and practice would be based on nursing conceptualization of family and would assist nurses in understanding and analyzing the genetic, behavioral, and environmental factors related to health risk or protection shared by family members. Such a tool would integrate information about the biological family, a group that shares genetic factors and may or may not share behavioral and environmental factors, with information about non-biologically related family members who share behavioral and environmental factors.

Such a tool would be consistent with ecological models of health, recommended by the Institute of Medicine (IOM) for use in research and practice to understand the linkages and relationships among the multiple determinants of health in the genomic era.[41] Ecological models of health draw on Bronfenbrenner's bioecological perspectives of human development to examine the interaction of multiple factors on human development.[42,43] In ecological models of health, the individual's social environment is conceptualized as a series of nested interacting systems.[44] The individual may be conceptualized as existing inside a small family system; his health is affected by the family system, and the family system is in turn affected by his health. The family system makes up an interacting component of an extended family system, which in turn is an interactive part of a community system. Health is understood as being affected by the interaction between biology, behavior, and environment.[45]

Ecological models play an important role in nursing research, for example, guiding nurse researchers in family-focused research exploring nuclear and multigenerational family health factors during transition to parenthood,[46] multigenerational influences on infant feeding,[47] and the influence of extended family and intergenerational factors on child health.[48] An example from nursing research demonstrates how defining family from an ecological perspective may be useful in creating a representation that is consistent with nursing conceptualization of family. Riesch, Anderson, and Krueger drew on an ecological developmental perspective to define *parent* in the following manner: "A parent is a person who brings up and cares for another which includes other individuals who function in a primary parenting role such as grandparents, stepparents, foster parents, and guardians."[49] This definition of parent is consistent with nursing conceptualization about families and reflects the diverse and changing structure of real families, but may not be represented in a pedigree, genogram, or any currently available computational tool available to nurses working with families, demonstrating the mismatch between tools currently available and real families.

Continued reliance on tools that narrowly define family as a biological unit limits nurses' ability to record and analyze the breadth of their knowledge about family and family history, obscures important components of nursing knowledge and practice, and hampers nurse researchers in their efforts to build new knowledge about family history and health. The development of computational tools based on nursing conceptualization will enable nurses to capture and build on their complex knowledge about real families. Nursing informatics research will play a key role in developing tools consistent with nursing conceptualization about families and other phenomena of interest to nurses. Delaney and colleagues stated that knowledge and methodologies from computer science must be embraced in order to represent the depth of nursing knowledge about phenomena.[50] To that end, work is in progress to create a computational formalization of family health history based on nursing conceptualization of family[51] which could serve as the foundation for more robust family history tools for nurses in research

and practice. Similar formalizations of other nursing phenomena may be forthcoming from nursing informatics research. Nurses in practice and research must now visualize the tools they need and communicate and collaborate with their nursing informatics researcher colleagues to ensure that the tools needed for nursing research and practice are developed and made available.

CONCLUSION AND RECOMMENDATION

In this article, we are asking nurses to use skills that they already possess—those of designing and using instruments that are conceptually congruent with their phenomena of interest—but to translate those skills to the informatics arena. Nurses must be mindful of the conceptualizations on which computational tools are based, be aware of what types of information may be missing or inaccurate and, at times, even reject the use of unsuitable tools as inconsistent with nursing knowledge and practice. As nurses reject existing tools, they have a unique opportunity to describe tools that would be consistent with nursing conceptualization and to collaborate with nursing informatics researchers to develop computational tools that will enable nurses to build sound nursing knowledge and provide optimal care. The development of these tools will be complex, requiring the combined expertise of nurse researchers, nurse clinicians, and nurse informaticists. Collaboration and communication are, therefore, vital.

As the use of computers in healthcare becomes routine and the amount of information nurses must locate, synthesize, and apply grows, nurses have a unique opportunity to ensure that computer systems support rather than hinder nursing research and practice. Nurses must critically consider the commitments on which their tools are based, recognize situations in which the commitments are inconsistent with nursing conceptualization, and speak up when a better tool is needed.

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