What should we teach about disability? National consensus on disability competencies for health care education

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Abstract

Background: Health care providers are unprepared to meet the health needs of patients who have disabilities. Disability training is needed, yet there is little agreement about what should be taught.

Objective: Establish a national consensus on what healthcare providers across disciplines need to know to provide quality care to patients with all types of disabilities (e.g., mobility, sensory, developmental, mental health).

Methods: People with disabilities, disability advocates, family members of people with disabilities, disability and health professionals, and inter-disciplinary health educators systematically evaluated and provided feedback on a draft set of disability competencies. Based on this feedback, competencies were iteratively refined.

Results: After two waves of feedback, six competencies, 49 sub-competencies, and 10 principles and values emerged that addressed topics such as respect, person-centered care, and awareness of physical, attitudinal, and communication health care barriers. An overwhelming majority (89%) agreed or strongly agreed that the disability competencies reflected the core understandings needed to provide quality care for patients with disabilities, were relevant across disability types (85%), and across health care disciplines (96%). Averaging evaluative feedback across competencies, participants reported that the competencies were important (98%) and clear (96%).

Conclusions: This consensus on what to teach is an important milestone in preparing a disability competent health care workforce. Future directions for research, training, and policy are discussed. When disability is included in health care education, the health care workforce will be prepared to deliver accessible, patient-centered, quality health care to patients with disabilities.

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researchers issued a call to action for inclusion of disability content in health care education to ensure students gain essential competencies to care for people with disabilities. We respond to this call.

Innovative disability curricula have been developed, evaluated, and published for health care education including medicine,10–13 nursing,14,15 social work,16,17 psychology,18,19 and interprofessional health students.20 Learning objectives, curricular content, and evaluation measures were developed independently for each curricular element. Agreement on what to teach about disability remains unansweried in part because inclusion of disability content has relied on the advocacy efforts of individual champions in health education.21 Approaching disability training from a competency-based education framework allows us to develop learning objectives based on the health needs of the community,22 people with disabilities. The first step in developing competency-based education is to explicitly map the specific health needs of people with disabilities to a set of competencies for the workforce in training.22 Fundamental educational standards, competencies, or learning outcomes on disability are needed to scaffold curricular content that produces the requisite knowledge, values, and skills in learners.22 Competencies for health care students that align with the health needs of people across the full range of disabilities are therefore necessary to ensure that learners have the capabilities necessary to provide high-quality care to patients with disabilities.

Developing draft disability educational standards

The Alliance for Disability in Health Care Education (Alliance) is a nonprofit membership organization comprised of interprofessional health educators and health care providers representing the disciplines of medicine, nursing, psychology, physical therapy, occupational therapy, and other allied health professions. The Alliance mission is to integrate disability content and experiences into health care education and training programs. The 2012 annual meeting of the Alliance focused on defining a process for developing education standards on disability for health care education. Twenty members representing disciplines of medicine, nursing, psychology, social policy, occupational therapy, and medical engineering formed work groups around key aspects of health care: disability frameworks, professionalism, disability rights, team-based care, and clinical assessment and care. Workgroups met monthly by phone and drafted educational standards. At the 2013 annual meeting, workgroup representatives presented and led discussions about the disability education standards that had been drafted. Four Alliance members then reviewed all workgroup materials and compiled a complete draft, which was reviewed and edited one final time by workgroup members. The final draft, which included 73 educational standards, was presented to members at the 2014 Alliance Annual Meeting. Recognizing the diversity of disability types and that health care needs span health professions and disciplines, the competencies were designed to be relevant for treating patients across the full range of disability (e.g., mobility, sensory, mental health, and developmental disabilities) and applicable to future physicians, nurses, and other allied health professionals (interprofessional).

Alliance members recognized the important milestone of developing disability competencies and discussed opportunities to gather broader stakeholder input, engagement, and awareness of the disability educational standards. The present study was designed to take this next step of eliciting input on disability educational standards from a large sample representing key disability stakeholders, including people with disabilities.

The purpose of the present study was to establish a broad consensus on the core disability competencies for health care education based on input from a diverse group of disability and health stakeholders.

Methods

There are no guidelines nor empirical bases for determining the key disability learning objectives in health care education. Consensus methods using the subjective opinions of a group of experts can serve to explore and push the edges of scientific knowledge.22 Consensus approaches are widely used in many domains including health care decision-making, developing educational standards, and developing quality indicators.24–27 Effective consensus building approaches are clear, systematic, and use the following elements23,24,28: 1) establishing a panel of topic experts, 2) soliciting the anonymous individual input of the panel members on a specific topic, 3) providing the impaneled experts with a synthesis of the group’s ideas/feedback and enabling another round of feedback, and 4) this synthesis reporting and revision/feedback process is repeated until a pre-set threshold for consensus is achieved. The aim of this study was to refine and obtain a consensus on essential disability competencies among disability stakeholders.

We used a consensus building technique and set a predetermined level of agreement of 75% or higher as defining consensus for each educational standard. We decided a priori to terminate the iterative feedback process when the average agreement across experts and across disability educational standards reached or exceeded 75%.

Participants

We sought input from a national cross-section of disability stakeholders to gain consensus on the disability competencies. We considered disability expertise to include people with lived disability experience (people with disabilities and family members) and people with professional experience in the disability and health field. Interprofessional health educators were included in the Wave 2 sample to align the disability competencies with existing educational standards. These health educators were included as subject experts who could respond to the suitability of language and content for their respective discipline, but not necessarily from a disability perspective.

Measures

Participant characteristics

Participants self-identified as a person with a disability, disability advocate, family member of a person with disability, disability professional, health professional, health educator, and/or other. We did not define these identities and participants could self-identify into more than one category.

Feedback survey

We created an online survey to gather overall agreement and specific feedback from panel members on the draft disability competencies. After reviewing the draft competency document, participants were asked to make a global appraisal on a four-point scale, To what degree do you think the competencies and their sub-competencies address the range of knowledge, attitudes, and skills necessary for health care students to appropriately and effectively address the needs of people with disabilities? This question was followed by two open-ended questions: Of the competencies and sub-competencies presented in the document, which, if any, do you feel should be addressed in greater depth? and What competencies or sub-competencies, if any, do you feel were fully missing from the document? Expert panel members were then asked a cross-disability question, The Alliance competency framework is intended to help providers care for people with a variety of disabilities, including behavioral, developmental, mobility, and sensory disabilities. To what
degree do you think the competencies are applicable to people across the full spectrum of disabilities? Panel members were then asked to rate, on a four-point scale, the following three questions for each competency: How important are the descriptions of Competency X and How clear are descriptions of Competency X? We provided the following definitions for importance: To ensure safe and quality patient care, and to practice the profession effectively; and clarity: Language level is clear and acceptable, and the terminologies used are accessible. The third question provided a free text opportunity to comment on specific passages in each competency and sub-competencies and suggest changes.

Because we reached out to interprofessional health care educators in Wave 2, we added the following question to the survey, The Alliance competency framework is intended to be cross-disciplinary. To what degree do you think the competencies are appropriate across health professions? This question was rated on a four-point scale and followed by this open-ended question, If you answered “Not at all” or “Somewhat” to question 6 above, what disciplines do you find underrepresented? Do you have suggestions for improvement?

Procedure

In October 2017, we identified and recruited disability stakeholders to refine the disability competencies. We sent 339 invitations to participate in Wave 1 through national disability networks including disability policy and advocacy groups and individuals, disability service organizations, and programs with a disability and health focus. Disability stakeholders completed a commitment form, agreeing to serve on the expert panel and to provide feedback on disability educational standards over a series of iterations until consensus was reached. Second, we sent panel members the draft disability competencies developed by the Alliance and a link to the anonymous online feedback survey. Participants were encouraged to contact the research team if they needed accommodations to fully participate in the panel. Third, after three reminders and four weeks, we closed the survey, analyzed Wave 1 data and revised the competencies based on expert panel feedback. Working together, the co-authors of this paper reviewed each comment provided in free text and made suggested revisions that were consistent with the intent of creating interprofessional and cross-disability competencies. When deliberating about proposed revisions, more weight was given to suggestions that were made by more than one panel member. Thus, both quantitative and qualitative criteria were used in the determination of consensus. Fourth, we recruited a group of interprofessional health educators to participate in Wave 2. Health educators were recruited through professional associations for medicine, nursing, speech and hearing, psychology, and through the Interprofessional Education Collaborative, which is comprised of health associations across 21 disciplines. Fifth, we sent the revised disability competencies to all participants from Wave 1, a summary of the changes made based on panel feedback, and a link to the Wave 2 feedback survey. The panel members recruited at Wave 2 were sent the revised Disability Competencies with a link to the feedback survey. Sixth, after three reminders and four weeks, we closed the survey and analyzed Wave 2 qualitative and quantitative data using the same process as in Wave 1. See Fig. 1 for the consensus study procedure and timeline.

Results

A diverse group of disability stakeholders was recruited to review and refine the disability competencies. From a total of 339 invitations, 75 participants were recruited in Wave 1 (22% response rate) including people with disabilities (n = 17), disability advocates (n = 27), family members of people with disabilities (n = 5), disability professionals (n = 32), health professionals (n = 31), and other (n = 12). The other category included researchers, public health professionals, and health administration professionals. It is important to note that the vast majority of respondents (90%) self-reported having more than one identity (e.g., person with a disability and health educator).

At Wave 2, 65 invitations were sent to interprofessional health educators and, of these, 38 accepted invitations (58.5% response rate) representing medicine (n = 7), nursing (n = 12), occupational therapy (n = 2), physical therapy (n = 2), social work (n = 1), psychology (n = 2), speech and hearing (n = 1), public health and policy (n = 9), and other health professions (n = 24), including pharmacology, nutrition, physician assistant, and recreation therapy.

Wave 1

Participant feedback on the draft competencies was quite positive at Wave 1. Table 1 shows the summary agreement ratings at Wave 1 and Wave 2 for global appraisal, cross-disability, interprofessional (only asked at Wave 2), and ratings for importance and clarity averaged across competencies. Because we recruited health educators to join the expert panel at Wave 2, these tables report agreement by the following three groups of expert panel members: members who committed to the Consensus study and completed Wave 1 but not Wave 2 review (Wave 1 ONLY), members who engaged in both Wave 1 and Wave 2 (Wave 1&2), and members who participated in Wave 2 only (Wave 2 ONLY). As shown in Table 1, among Wave 1 ONLY and Wave 1&2 groups combined, 83.6% agreed or strongly agreed at Wave 1 that the disability competencies addressed the range of knowledge, attitudes, and skills necessary to care for people with disabilities (global appraisal) and 70.8% agreed or strongly agreed that the disability competencies were applicable across the full range of disability types. Table 2 lists the ratings for each competency across the three participant groups at Wave 1. Averaging across the 5 competencies, we found approximately 95.3% of panel members agreed or strongly agreed that the competencies were important and 81.5% agreed or strongly agreed that they were clearly written.

We received 354 open-ended comments and suggestions for changes to the disability competencies in Wave 1. Revisions in response to these open-ended comments included adding definitions and examples to improve clarity and adding learning outcomes on behavioral health, supported decision making, and diversity and cultural competence. We revised the learning outcomes on disability framework and history to focus on disability rights and the independent living movement. Finally, we split a longer competency that addressed clinical assessment and clinical care into two competencies. The Alliance competency document reviewed in Wave 1 included 5 competencies and a total of 73 subcompetencies. Revisions based on Wave 1 feedback resulted in 6 competencies and a total of 55 subcompetencies. Although Wave 1 ratings approached our predetermined criteria of 75% agreement for consensus, we considered the revisions based on qualitative feedback to be substantive and therefore decided to pursue a second wave of feedback.

Wave 2

A total of 36.5% (n = 27) of Wave 1 participants also participated in Wave 2. In addition, 38 interprofessional health educators provided feedback at Wave 2 only. As shown in Table 1, participant feedback improved at Wave 2. The iterative progress toward
Fig. 1. Consensus study procedure and timeline.

Table 1 - Summary Consensus Agreement across Waves and Expert Panel Member groups.

<table>
<thead>
<tr>
<th>Expert Panel Groups</th>
<th>Global</th>
<th>Cross-disability</th>
<th>Inter-professional</th>
<th>Importance (competency average)</th>
<th>Clarity (competency average)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wave 1</td>
<td>84.7%</td>
<td>69.6% (32/46)</td>
<td>96.5%</td>
<td>85.9%</td>
<td>85.9%</td>
</tr>
<tr>
<td>Wave 1 &amp; 2</td>
<td>81.5%</td>
<td>73.1% (19/26)</td>
<td>Not asked</td>
<td>93.3%</td>
<td>74.1%</td>
</tr>
<tr>
<td>Wave 2</td>
<td>83.6%</td>
<td>70.8% (21/27)</td>
<td>95.3%</td>
<td>81.5%</td>
<td>94.5%</td>
</tr>
<tr>
<td>Wave 1</td>
<td>90.9%</td>
<td>80.0% (24/30)</td>
<td>98.2%</td>
<td>96.6%</td>
<td>96.0%</td>
</tr>
<tr>
<td>Wave 1 &amp; 2</td>
<td>88.9%</td>
<td>85.2% (23/27)</td>
<td>98.7%</td>
<td>96.6%</td>
<td>96.0%</td>
</tr>
<tr>
<td>Wave 2</td>
<td>90.9%</td>
<td>85.2% (23/27)</td>
<td>98.7%</td>
<td>96.6%</td>
<td>96.0%</td>
</tr>
</tbody>
</table>

Wave 1 & 2 lines were bolded to help the reader identify and compare the subgroup of panel members who engaged in both Waves of the interactive process. This subgroup is particularly important because it demonstrates a growing consensus.

* Percentages represent the upper ends of rating scale (e.g., Very Well/Extremely Well, Mostly Important/Very Important, and Mostly Clear/Completely Clear).

To what degree do you think the competencies and their sub-competencies address the range of knowledge, attitudes, and skills necessary for health care students to appropriately and effectively address the needs of people with disabilities?

See Table 2 to find ratings for each competency.
consensus is illustrated by the change in the Wave 1 & 2 group from Wave 1 to Wave 2. Averaged across the three membership groups, an overwhelming majority (88.9%) agreed or strongly agreed that the disability competencies addressed the range of knowledge, attitudes, and skills necessary to care for people with disabilities, were applicable to the care of patients across the full range of disability types (85.2%), and were relevant to education across health disciplines (96.3%). Averaged across competencies, panel members rated the competencies as important (98.2%) and clear (96.0%). As with Wave 1, we reviewed the open-ended responses and collectively decided on changes based on the intent of the disability competencies. From a total of 136 individual responses, changes were made to include social and environmental health determinants, the role of support providers and supported decision making in patient-centered care, and awareness of the increased risk of abuse for people with disabilities. Finally, we made minor edits to ensure the disability competencies were applicable to healthcare across the lifespan. These changes resulted in the addition of four subcompetencies. Because of the very high rate of agreement among our expert panel and because fewer and only minor changes were suggested, we determined that consensus was reached in April 2018.

Disability stakeholders converged upon six competencies (see Table 3) and 59 subcompetencies, including ten guiding principles and values essential to providing quality care to people with disabilities.28 The Core Competencies on Disability for Health Care Education and supporting material are available online, go.osu.edu/corecompetenciesdisability-learnmore.

Discussion

Disability education for future health care professionals offers an actionable step toward improving the health of children and adults with disabilities. We gathered input from a wide range of disability stakeholders to develop consensus-based disability competencies for interprofessional health care education. This consensus represents a milestone in the path toward disability competent healthcare by suggesting what health care students need to learn about disability. These competencies can guide the next steps of including disability competencies in interprofessional education standards, as well as curriculum development and evaluation.

There are strengths and weaknesses of this study that should be considered when interpreting these results. One limitation was the low retention rate from Wave 1 to Wave 2 (36.5%) among our expert panel members. This, together with the fact that we
### Table 4
Alignment of disability competencies and LCME

<table>
<thead>
<tr>
<th>LCME Standard 6: Competencies, Curricular Objectives, and Curricular Design</th>
<th>Disability Competency 3.6</th>
<th>Disability Competency 3.7</th>
<th>Disability Competency 3.8</th>
<th>Disability Competency 4.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Required Clinical Experiences</td>
<td>Ensure that healthcare providers and support staff members are trained to provide services that meet the needs of the patient with a disability (e.g., knowing how to appropriately transfer a patient with a mobility limitation to an exam table).</td>
<td>Providers recognize their own need for further training and/or skill development in caring for patients with disabilities and take action to address those needs based on current best practices.</td>
<td>Recognize issues related to legal guardianship (e.g., consent to treatment, HIPAA, privacy) in the health care system.</td>
<td>Describe impact of teams and the unique and discipline-specific responsibilities of team members in addressing health needs of patients with disabilities, in partnership with the patient as a central member of the team.</td>
</tr>
<tr>
<td>Organ Systems/Life Cycle/Primary Care/Prevention/Symptoms/Signs/Differential Diagnosis, Treatment Planning, Impact of Behavioral and Social Factors</td>
<td>Demonstrate skill in performing a history and physical exam (PE), modifying it as needed to provide equally effective care while accommodating for mobility, sensory, cognitive, and/or behavioral issues.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Critical Judgment/Problem-Solving Skills</td>
<td>Assess the social environment of patients with disabilities to understand the impact of significant relationships and social networks on health outcomes.</td>
<td>Recognize that disability should not limit self-determination in end-of-life care for people with disabilities, regardless of disability type and severity. Offer treatment options in the same way options would be presented to similar-aged peers without disabilities.</td>
<td>Assess the physical environment of people with disabilities, recognizing that the patient’s socioeconomic status is a determinant of his/her functioning and independence and also affects health and safety.</td>
<td></td>
</tr>
<tr>
<td>Societal Problems</td>
<td>Recognize that children and adults with disabilities are vulnerable to abuse. The nature of abuse may be verbal, financial, physical and/or sexual. Abuse often goes unreported because the person with a disability may depend on the abuser for activities of daily living or social support.</td>
<td>Recognize that disability should not limit self-determination in end-of-life care for people with disabilities, regardless of disability type and severity. Offer treatment options in the same way options would be presented to similar-aged peers without disabilities.</td>
<td>Assess the physical environment of people with disabilities, recognizing that the patient’s socioeconomic status is a determinant of his/her functioning and independence and also affects health and safety.</td>
<td></td>
</tr>
<tr>
<td>Cultural Competence and Health Care Disparities</td>
<td>Describe disability as an aspect of diversity/cultural identity and contrast with historical views of disability as merely a negative health outcome.</td>
<td></td>
<td></td>
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<tr>
<td>Medical Ethics</td>
<td>Explore and mitigate one’s own implicit biases, and avoid making assumptions about a person’s abilities or lack of abilities and lifestyle.</td>
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</table>

The faculty of a medical school ensure that the medical curriculum provides content of sufficient breadth and depth to prepare medical students for entry into any residency program and for the subsequent contemporary practice of medicine.
Table 4 (continued)

<table>
<thead>
<tr>
<th>LCME Standard 6: Competencies, Curricular Objectives, and Curricular Design</th>
<th>Disability Competency 2.3</th>
<th>Disability Competency 2.6</th>
<th>Disability Competency 3.3</th>
</tr>
</thead>
<tbody>
<tr>
<td>The faculty of a medical school define the competencies to be achieved by its medical students through medical education program objectives and is responsible for the detailed design and implementation of the components of a medical curriculum that enable its medical students to achieve those competencies and objectives. Medical education program objectives are statements of the knowledge, skills, behaviors, and attitudes that medical students are expected to exhibit as evidence of their achievement by completion of the program.</td>
<td>Demonstrate communication strategies to best meet the needs/abilities of the patient. Seek out and implement appropriate resources, including interpreter services, to communicate effectively using understandable language. Adjust schedule to allow extra time as needed.</td>
<td>Recognize that some patients with disabilities may benefit from supported decision-making. Demonstrate skill in engaging the patient and caregivers in the supported decision-making process.</td>
<td>Plan for accessible communication in all aspects of the healthcare encounter including scheduling, intake, responding to and asking questions, and follow-up care. Avoid technical jargon.</td>
</tr>
<tr>
<td>LCME 7.8 Communication Skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LCME 7.9 Interprofessional Collaborative Skills</td>
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<td></td>
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</tbody>
</table>

recruited a new group of health educators to participate in Wave 2, meant that relatively few panel members engaged in the iterative consensus process. Despite this limitation, strong consensus on the competencies was found as shown in Tables 1 and 2 for panel members who participated in Wave 1 only, Wave 2 only, and both Wave 1 and Wave 2. A second limitation is that demographic information was not collected from panel members. This oversight limits our ability to report on the diversity and representativeness of the expert panel. Strengths of this study was the engagement of a large expert panel representing people with professional disability expertise and lived disability experience. Health educators were included to help align the disability competencies to existing educational standards. To our knowledge, this is the first study attempting to develop disability competencies for health care education with broad stakeholder input.

Including disability training in interprofessional health care education is important because all health care professionals encounter patients with disabilities and should demonstrate competence. Disability competent care promises to improve health care for people with chronic health diseases and functional limitations as well as for people with disabilities. Disability competence is well-aligned with the universal goal of health care training programs to prepare the workforce to meet population health needs. As shown in Table 4, the disability competencies align with the Liaison Committee on Medical Education standards. Including disability competencies in all accreditation, licensure, and health education certification standards would engender systemic change and motivate the continued education on disability among practicing health care providers.

Proposing to add disability objectives and curricular content will likely meet with resistance owing, in part, to competing demands for content in already overcrowded curricula. Importantly, we do not recommend separate disability courses, clinical placements, or new specialties. The most efficient and effective approach to disability competence would recognize disability as an aspect of population diversity, akin to race or ethnicity. Many of the topics addressed in the disability competencies are currently taught in health care education, but not applied to patients with disabilities. Disability content could be seamlessly woven into discussions of health equity, professionalism, patient-centered care, social determinants of health, intersectionality, and cultural competence. Recently, Krishnan and colleagues established guidelines for revising case-based courses to deliver critical concepts around race and culture. Aquifer adopted these guidelines, which may impact virtual-case-based courses used by over 95% of U.S. medical schools. A similar case-based approach could be used to deliver critical disability concepts. Disability cases, small group activities, and journal club recommendations are available as online trainings. Among disability training approaches, providing interprofessional health care students the opportunity to meet people with disabilities had the most significant impact. It is important to recruit lecturers, panel members, and/or standardized patients from the disability community. Asking standardized patients to feign disability lacks authenticity and may inadvertently reinforce negative stereotypes about people with disabilities. Furthermore, actors without disabilities are not credible in portraying aspects of disability such as atrophied muscles, poor head control, deafness, blindness, contractures, spasticity, dysarthric speech, or the use of communication devices or interpreters. Further work is needed to develop curricula content and resources that teach the core disability competencies.

Producing a disability competent health care workforce will require widespread adoption of the disability competencies in health care education. Future research is needed. First, work with professional accreditation and licensure bodies is needed to embed...
disability in health education standards. Second, research is needed to develop protocols to evaluate curricular elements and disability competence (e.g., items for board and licensure examinations). Third, professional development on disability will be critical to prepare faculty to teach these competencies. Finally, clinical outcomes research is needed to evaluate the relationships between disability competence, quality health care, and patient outcomes.

Conclusions

This work represents an important milestone in the creation of a disability competent health care workforce. We submit this work hoping that these competencies will guide the development and evaluation of disability content in interprofessional health education. Achieving a disability competent health care workforce promises better health care and better health outcomes for people with disabilities.

Presentations

These findings were briefly summarized in a Commentary that was published in DHJO (Neill Bowen, Havercamp, Karpaik Bowen, Nye, 2020). These findings were presented, in part, at the following professional meetings:


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Declaration of competing interest

The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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