

Empowering Immigrant Patients with Disabilities: Advocating and Self-Advocating

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This article explores how to improve health care for immigrant patients with disabilities from an empowerment framework that encompasses both advocacy and self-advocacy. Immigrants with disabilities face multiple challenges in adapting to life in a new country. In addition to obstacles related to their disabilities, they must overcome cultural and linguistic barriers, acculturative stress, prejudice and discrimination. Furthermore, many recent immigrants have limited financial resources. They also confront many of these same barriers in the health care system along with numerous structural, environmental, and process-related obstacles. Health professionals can empower immigrant patients with disabilities in multiple ways, including (a) providing culturally sensitive services; (b) communicating to them in their native language; (c) about Americans with Disabilities Act, Individuals with Disabilities Education Act and other federal and state laws that protect the rights of individuals with disabilities; and (d) informing immigrant patients about their rights and available resources. Most importantly, health professionals can advocate for these patients' healthcare needs and help them to develop the skills to self-advocate. Self-advocacy can be facilitated by means of training in assertiveness and related communication skills, which are consistent to the patients' goals and cultural values.

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INTRODUCTION

The mission of health professionals, including those in the medical and mental health disciplines, is to improve the health and wellbeing of all patients. This is a particularly challenging task with patients at risk of discrimination and poor health outcomes, such as individuals with disabilities, immigrants, and individuals living in poverty.³³ For these groups to achieve better health outcomes, health professionals need to understand their challenges in life and in the healthcare system, and empower them to overcome adversity. This article explores how advocating and self-advocating can empower one particularly vulnerable population, immigrant patients with disabilities.

According to Americans with Disabilities Act (ADA),¹ (the federal civil-rights law that prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities), disabilities encompass physical and/or mental impairments that substantially limits one or more of the major life activities of the individual. Disabilities include intellectual impairment, hearing impairment, vision impairment, orthopedic impairment, speech impairment, learning disabilities, HIV/AIDS, and other health or physical

conditions, and psychiatric disorders (e.g., major depression, bipolar disorder, panic and obsessive-compulsive disorders, schizophrenia). Another federal civil-rights law, the Individuals with Disabilities Education Act (IDEA),² protects the educational rights of individuals with disabilities: This Act identifies thirteen categories of disabilities, including autism, developmental delay, emotional disturbance, hearing impairment, intellectual disability, other health impairment, specific learning disability, and speech or language impairment. Early intervention, special education and related services under IDEA serve 6.5 million eligible infants, toddlers, children and youth with disabilities. In the 2010 census, 56.7 million individuals reported a disability with more than half of them reporting a severe disability.³

In addition to the challenges inherent to the disabilities, individuals with disabilities often encounter individuals, who have little or no understanding of their disability. As a result people often do not know how to appropriately interact or respond to a person with a disability.⁴ Individuals with disabilities may also experience prejudice and discrimination, such as ableism.⁴ The latter implies that people with a disability are inferior⁵ and less competent than people without a disability.⁶ Individuals with disabilities are also more likely to be unemployed and live in poverty.^{7,8} In addition, individuals with psychiatric disorders often encounter biases.⁷

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Children and older adults with disabilities are at higher risk of experiencing maltreatment, such as neglect and physical, emotional and sexual abuse.^{9,10} Furthermore, children with disabilities are more likely to be bullied,¹¹ and older adults with disabilities are more likely to be financially exploited.¹⁰ Although individuals with disabilities confront many challenges in life and specifically with the U.S. healthcare system, immigrants with disabilities also face important challenges as new arrivals to the country. In this article, immigrants are defined as foreign born individuals who have migrated to the United States for permanent residence. Currently, 42.4 million immigrants live in the United States.¹² The largest group of immigrants is from Mexico (28%), followed by Asia, Central and South America, Middle East, Africa, and Europe.¹² Despite their differences in country of origin, race, culture, religion, gender, age, and other demographic features, immigrants are likely to face some common challenges in the new country, including cultural and linguistic barriers, acculturative stress, prejudice and discrimination, and limited financial resources.^{13,14}

Immigrants with disabilities are a unique group, whose health care needs are put at additional risk by the complexity of having a disability. As Hwang et al¹⁵ point out, non-immigrant patients with disabilities face numerous structural, environmental and process-related barriers to health care. These include (a) problems with inaccessible examination rooms, (b) lack of appropriate equipment (e.g., scales that accommodate wheelchairs), (c) lack of convenient access to care, (d) dissatisfaction with physicians' understanding of their health condition, and (e) physicians' reluctance to take the time to answer their questions. These barriers have many negative personal and social consequences for patients with disabilities.¹⁶ For instance, Neri and Kroll found that patients whose disabilities impaired their mobility began to curtail their social roles because they were no longer able to move about with sufficient ease or fulfill their existing or desired roles in their communities.¹⁶ In addition, health care workers may not have sufficient training to provide culturally sensitive care or know how to communicate effectively with immigrant patients.¹⁷ Different conceptualizations in the nature and causes of illness and disabilities (e.g., seeing disability from a moral model, a medical model, or a minority model⁴¹) between the health care provider and the immigrant patient can lead to communication barriers, which in turn can lead to obstacles in accessing appropriate care.^{17,18} Finally, in addition to these challenges, immigrants may also have inadequate health insurance and may struggle to understand and use the complex health care system in the US.¹⁹

The diversity among individuals with disabilities makes the challenge of providing personalized care to them even more daunting. They differ with respect to age, gender, socio-economic status, culture, religion, and type and severity of disabilities. In addition to the aforementioned diversity, immigrants with disabilities differ in native language, proficiency in English, acculturation level and acculturative stress. Thus, each individual patient should be viewed in

his/her ecological context, and his/her unique cluster of challenges and resources must be considered when providing health services. Given the vulnerability of immigrant patients with disabilities, health professionals should strive to help them develop life-long coping skills. One overarching approach to this task is to empower these patients. Empowerment, as defined by Page and Czuba (1999),²⁰ means a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people for use in their own lives, their communities, and in their society by acting on issues that they define as important. Health professionals can empower patients by (a) providing culturally sensitive services, (b) removing language barrier in communication (e.g., using the patient's own language), (c) learning about ADA, IDEA and other federal and state laws that protect the rights of individuals with disabilities, and (d) informing immigrant patients with disabilities about their rights and supporting resources. These patients' knowledge about relevant state and federal laws as well as their knowledge about rights and supporting resources will be advanced if health care professionals understand the importance of communicating this information.

TRAINING AND RESOURCES

To facilitate the preparation of healthcare professionals to communicate this information and improve the healthcare literacy of patients, the federal government has developed a Health Literacy Universal Precautions Toolkit.²¹ This toolkit contains several training modules, such as using specific communication methods (e.g., the 'teach-back' method) and addressing language differences. Health care organizations can collaborate with universities, which have public health schools, to implement this training for health care professionals.

Health professionals and immigrant patients can use other online resources to learn about Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA). For instance, the Department of Public Social Services of New York provides information regarding ADA. This website (<http://www.ladpss.org/dpss/civilrights/ada.cfm>) has information on how to request a reasonable modification to accommodate a disability. The information is translated into multiple languages (i.e., Spanish, Armenian, Cambodian, Chinese, Farsi, Korean, Russian, Tagalog, Vietnamese). The U.S. Department of Education provides comprehensive resources on the IDEA website (<http://idea.ed.gov/>) to ensure that children with disabilities receive free and appropriate services relative to their needs. State educational agencies, such as the Massachusetts Department of Elementary and Secondary Education, have the Individualized Education Program (IEP) forms and notices, as well as a parents' rights brochures, translated into multiple languages (see, e.g., <http://www.doe.mass.edu/sped/iep/tforms.html>). These forms are accompanied by a glossary corresponding to each language, which translates common special education terms. In addition, health professionals and immigrant patients can access online translations of medical vocabulary. One

example of this type of tool is the Mandarin Vocabulary List for Common Medical Terms (the following is the website: http://mandarin.about.com/od/vocabularylists/tp/medical_terms.htm).

PROVIDING CULTURALLY SENSITIVE AND TIMELY ASSESSMENT OF DISABILITIES

Immigrant patients with disabilities need culturally sensitive and timely diagnoses. Unfortunately, it is very challenging for health professionals to make culturally sensitive diagnoses due to cultural and linguistic barriers and the scarcity of appropriate assessment tools for specific populations.²² Cultural awareness, knowledge and skills are recognized as preconditions for providing culturally sensitive diagnoses.⁴ Therefore, health professionals should increase their own cultural awareness, knowledge and skills, as well as follow the guidelines of nondiscriminatory assessment.^{2,23} The first step in conducting an appropriate assessment of an immigrant patient's disabilities or mental health problems is to determine the individual's language proficiency in English and his/her native language as well as his/her acculturation level. This information will inform the selection of assessment methods and instruments.^{22,23} Zhang and Cai²⁴ provide an overview of how to assess an individual's acculturation level. Li and Wang²⁵ are a good resource for assessment procedures that conform to IDEA's requirements for diagnosing learning, speech and language, cognitive, developmental, and emotional disabilities. The book, *Guide to Psychological Assessment with Asian Americans*,²² provides specific guidelines on how to conduct culturally appropriate assessment or select instruments for Asian immigrant patients. The book also provides a comprehensive review of a wide range of instruments in terms of cultural validity for Asian immigrants.

NEED FOR ADVOCATING AND SELF-ADVOCATING

Advocacy, that is, speaking for an individual or a group who does not have the ability to self-advocate, is an ancient concept, dating back to the orators of ancient Athens and the juris consults of the Roman Republic. Advocates use their expertise and social capital to bridge the gap between the needs of those who may lack this power, and a system that requires specialized knowledge by those who wish to access it. Most health care professionals feel an obligation to advocate for their patients.²⁶ Although this can be a controversial and complex process, requiring clinicians to juggle ethical issues such as equity and risk in a market-based health care system, effective advocacy can be critical in ensuring that the needs of vulnerable populations are met. Immigrant populations can be vulnerable for a variety of reasons including their socio-economic status, immigration status, level of English proficiency, the extent to which their community is marginalized in the US, as well as federal, state, and local policies. The latter policies may limit their access to healthcare.^{27,28} It is important to acknowledge that not all immigrants have the same needs; those who are well educated and well versed about their rights in the American systems and have access to financial resources may be well equipped to self-advocate. However, immigrants who

experience multiple disadvantages are at greater risk of not having their needs met.

As a result of these complex contextual factors, advocating for the needs of immigrant patients with disabilities can be a daunting task for health care providers. However, when patients are able to work with physicians to participate effectively in the decision making process, they are able to share the burden of advocacy through the process of self-advocacy.^{29,30}

According to Field,³¹ "Self-advocacy ... refers to taking action on one's own behalf; acts of self-advocacy lead to greater self-determination" (p. 42). In other words, self-advocacy is the act of finding one's voice and seeking resources to meet one's needs without compromising one's dignity. In the U.S. cultural context, self-advocacy and self-determination are valued attributes, particularly for individuals with disabilities, who might otherwise become marginalized.^{32,33} With respect to health care, even something as basic as asking for clarification about medications, or volunteering information about one's health history or allergies, can be a challenging task of self-advocacy. The 15-minute standard primary care visit leaves physicians and patients with very little time, and thus requires clear, precise, time-efficient, and reciprocal communication from both to ensure the best possible outcomes.

When patients and physicians are able to function as equal partners in this communication, the outcome is optimized in the relationship. Thorne and Robinson³⁰ found that reciprocal trust between health care professionals and patients with complex, chronic conditions increased when there was an "intimate and collegial interpersonal relationship" (page 784). In the context of such a relationship, Thorne and Robinson found that physicians and health care professionals came to trust the competence of patients and to view them as experts about their own health because of the reciprocal communication and trust that was fostered by the patients' ability to express their knowledge and needs with authority and autonomy. However, research findings also suggest that not all physician-patient communication is open and reciprocal.³⁴ For instance, physicians' communication styles can have an impact on patient participation, and some patients have reported feeling that physicians dominate the discussion during office visits. Advocacy and self-advocacy might help prevent this type of negative interaction.

SELF-ADVOCATING

In order to self-advocate the patient needs to: (a) know what is wanted or needed, (b) know what the patient is legally entitled to receive, and (c) have the ability to achieve the goal, that is, get what is wanted in an effective manner.³⁵ Knowing what one wants and/or needs can be a complex process, particularly for marginalized populations such as immigrants with disabilities. Patients may require assistance with transportation to medical appointments, paying for medical care, understanding prescriptions and instructions, and

understanding why the physician is choosing a specific method of treatment. Their needs may include being (a) treated with dignity and respect despite their marginalized lives; (b) listened to in an attentive and reflective manner that accounts for their fears, hopes and beliefs; and (c) reassured that they will receive a measure of relief.

Sometimes, a patient's knowledge of his/her wants and needs may be at odds with what the medical community deems to be appropriate treatment. For instance, some patients with disabilities may need mental health services to cope with their disability, but may not want it because they do not trust or understand the process. Similarly, patients with disabilities may also not always realize that their rights are protected by a variety of statutes including the ADA, the Affordable Care Act, and Association of American Physicians and Surgeons' Patients Bills of Rights.³⁶ When they experience injustices such as lack of access, they may not know that there is recourse. Immigrant patients often need counseling and education about their options both with respect to what treatment is available in the health care market place, as well as what they are entitled to by law. Individuals from parts of the world where healthcare options are limited, or where no established legal mandates protect the rights of patients with disabilities, may not understand how to use a system where these things are different. In order to self-advocate effectively, patients need to know their options and their rights.

Finally, the power differential in the physician-patient relationship plays a major role in determining whether patients are able to self-advocate. For example, it is common practice for physicians to use first names when referring to patients, whereas patients are expected to use the physician's professional title. In many cultures around the world, lay people are taught to respect, even revere, professionals such as physicians, lawyers, and teachers. It is essential to recognize when relative status, along with other factors discussed here, forms a barrier to communication. Although it is known that effective physician-patient communication is a significant factor in successful health care delivery, many patients report that they are dissatisfied with the way their physicians communicate with them about their treatment, and many physicians may overestimate their competence in this regard.³⁷ Findings by Ha and Longnecker suggest that when patients are empowered to collaborate with their physicians in a dynamic, reciprocal collaborative communication, this enhances the outcome for the patient and the satisfaction with the physician.³² Educating physicians, nurses and other health care professionals about communication styles that vary across cultures, and sensitizing them to the mindset of the patient are also important, and should be included as part of medical training.

Specifically, physicians would benefit from understanding how to recognize and navigate the major linguistic and cultural barriers that may separate them from their patients. Patients, particularly when they are worried or anxious about

medical issues, or when they need to discuss/disclose personal matters, may benefit from communicating in their preferred language. Even those who have sufficient competence with social communication in English may require additional supports for critical or difficult medical discussions. Awareness of cultural differences that lead to differences in communication styles is also essential for physicians. For instance, a smile does not indicate the same thing in all cultures.⁴ In Eurocentric cultures, a smile may indicate amusement or a greeting whereas in African or Asian cultures, a smile may also indicate embarrassment or shame. Some of these issues can be addressed through the use of interpreters or cultural brokers. However, it is critical to ensure that any additional professionals who are brought into the doctor-patient relationship do not jeopardize the delivery of health care services or the privacy of the patient.

ASSERTIVENESS: ESSENTIAL SKILLS FOR ADVOCACY AND SELF-ADVOCACY

Assertiveness is defined as "direct, firm, positive - and when necessary persistent - action intended to promote equality in person-to-person relationships."³⁸ Assertiveness is often mistakenly confused with aggression. However, assertiveness is the adaptive 'middle ground' between the extremes of passivity and aggressiveness.³⁸ Assertiveness has the potential to empower immigrant patients and professionals overcome at least three important challenges to advocacy. First, assertiveness can help the immigrant navigate the aforementioned structural and process-related barriers to health care. Passivity often does not succeed with large bureaucracies. Second, assertiveness emphasizes the mindset that all person-to-person relationships should be characterized by equality. The aforementioned power differentials between the patient and the health care professional and within the healthcare professions (e.g., between a nurse and physician), suggest that effective advocacy and self-advocacy in the health care system require striving for equality in interpersonal relationships. Third, assertiveness is conceptualized as a set of communication skills that is put into action. These skills are relevant to improving the communication between patient and health care professional and between health care professionals. Actions intended to overcome these challenges may not be initially successful. Thus, the concept of assertiveness encompasses the notion that the patient or professional needs to be resilient and persistent to accomplish his/her aims.

A reasonable ability to assert oneself is an implicit assumption of several of the "rights" of the Association of American Physicians and Surgeons' Patients Bills of Rights,³⁹ including the rights to "seek consultation with the physician(s) of their choice", "contract with their physician(s) on mutually agreeable terms" and "refuse medical treatment." Although it is important to have a statement supporting such rights and to inform immigrants in a language that they understand about these rights, the information alone is no guarantee that individuals will feel empowered to advance those rights or have the skills to effectively use them.

Fortunately, research indicates that individuals can learn assertiveness skills. Although no published research on assertiveness is available with respect to immigrants with disabilities, assertiveness training has been shown to be effective with both professionals⁴⁰ and patients,³⁹ and in different cultural contexts.⁴¹ McIntyre, Jeffrey and McIntyre,⁴⁰ for example, reported that a five-session assertiveness training program in the US. increased the assertiveness skills of professional nurses. Similarly, Lin et al.⁴¹ found that an eight-session assertiveness training program in Taiwan improved the assertiveness skills of nursing and medical students. Furthermore, Lin et al.³⁹ found that a four-week training program with psychiatric patients resulted in a statistically significant increase in their assertiveness immediately after training and at a one-month follow-up. In addition, individuals, who are assertive, are more likely to be treated with respect and fairness.⁴² Thus, being assertive increases the likelihood that an individual will feel empowered to affect change. More specifically, having assertiveness skills and the confidence to use those skills can potentially improve the health literacy and outcomes of immigrants with disabilities by empowering them to (a) ask questions, (b) collaboratively make actions plans related to their health needs, (c) provide health care professionals with feedback, and (d) seek other support services (e.g., literacy training).

Assertiveness training often incorporates modeling and cognitive and behavioral rehearsal.⁴¹ In regard to the cognitive component, training might include positive statements about the impact of their behaviors because expectations about the outcomes of assertive behavior can influence the extent to which a person exhibits that behavior.⁴³ 'When I am assertive, people respect me' is example of a positive self-statement that can be taught to an individual.

In addition to expectations, apprehension can impact one's assertiveness.⁴³ In these cases, individuals can be taught to use applied relaxation techniques to reduce their anxiety about being assertive, such as identifying the physical symptoms of anxiety related to being assertive, and then relaxing one's muscles to lower the anxiety.⁴⁴

The most common approach to helping individuals become more assertive is to teach them the behavioral fundamentals of an assertive communication. In this regard, Alberti and Emmons³⁸ place particular emphasis on how the message is delivered as evidenced by the following guidelines.

- **Eye contact** - Look directly at the person when you speak, but do not stare or continuously make eye contact.
- **Body posture** - Use an erect posture while facing the other person. Avoid slumping or a passive body position.
- **Distance/Physical Contact** - Do not approach too closely, otherwise the other person may feel threatened.
- **Gestures** - Emphasize your point with a relaxed use of gestures, which might serve to underscore the

importance of your message.

- **Facial Expression** - Match your facial expression to the seriousness of the message. When the facial expression and the words are incongruent, the message loses its impact.
- **Voice Tone, Inflection and Volume** - Avoid whiny or angry tones. Avoid raising your pitch at the end of sentences. Avoid being too soft or too loud.
- **Fluency** - Practice a smooth flow of speech when you are preparing for a stressful situation.
- **Timing** - Strive for spontaneous assertion, but beware of when your message should be conveyed in a private setting. The more promptly you address the issue, the more likely there will be a prompt resolution.
- **Listening** - After you have spoken, use active listening (e.g., nodding your head) and fully attend to what the individual is saying. Try to understand the individual's message before responding.
- **Thoughts** - Affirm that it is a good idea for people to assertively express themselves. Affirm that you have the skills to be assertive.
- **Persistence** - Some situations may not be resolved in a single encounter. Therefore, you need to be prepared to repeat your assertive communication in the future.
- **'I' messages** - Whenever possible, use "I" phrases and sentences to avoid blaming and causing the other person defensive.

According to Alberti and Emmons³³ the verbal dimension of an assertive message has three parts:

- Your understanding of the other person's opinion/perspective
- Your rationale for 'refusing' or 'requesting'
- Your *unambiguous* statement of a refusal or request

Before introducing any of these assertive behaviors to an immigrant, it is advisable to assess his/her readiness for learning the behaviors, including their compatibility with the person's cultural values. After this assessment, the trainer should (a) identify what behaviors are culturally appropriate to teach to the immigrant at the present time, (b) explain the importance of these assertive behaviors, and (c) then demonstrate their use. These steps would be followed by the trainee's rehearsal of the behaviors in the context of role plays, during which the trainer might enact the role of a health professional. The role play is often followed by a debriefing, which would entail the trainee's self-evaluation of his/her performance and feedback from the trainer. Feedback is instrumental in correcting self-misperceptions about the extent to which one's behavior is passive, aggressive or appropriately assertive.⁴⁰

A trainer's lack of sensitivity to the cultural values of an immigrant can negatively impact the immigrant's rapport with the trainer, and thereby jeopardize the success of the training.⁴¹ If a particular assertive behavior is not valued by the trainee, then the trainer must be careful not to create a conflict between the trainee's cultural values and the goals of

the training. In some Latino and Asian⁴⁷ cultures, for example, respecting authority figures is such an important value,⁴¹ that it might be very difficult for these individuals to question the decisions of a health care professional. In these instances, it may be advantageous to help the trainee explore the situations in which it is acceptable to question an authority figure's decision, and how one can communicate reservations without diminishing one's respect for the health care professional. Although making eye contact in the majority culture of the US. is considered appropriate behavior, in other cultures that type of non-verbal behavior may be considered disrespectful.⁴⁸ Thus, the trainer must be sensitive to these cultural differences and adjust the training accordingly. It is also possible that the trainee might not be ready to learn a specific a behavior at the beginning of the training, but he/she may be more receptive to learning that skill at later point in time. Thus, it is good practice to periodically reassess someone's readiness to learn a behavior.

Women immigrants may find assertiveness training particularly challenging because in many cultures women anticipate a social backlash for exhibiting assertive behavior⁴⁹ and in some cultures women may even be at risk for physical harm if they exhibit these behaviors. Although a health professional is unlikely to punish them for being assertive, these women may nevertheless be worried about the negative consequences of their assertiveness. However, research also indicates that women are less apprehensive about advocating for others than for themselves.⁴⁹ Given this finding, an advocate might be able to help these women shift their frame of reference about assertiveness from self-advocacy to a means of advocating for their families and people that they care about. In other words, a trainer or advocate could help these women understand that when they advocate for their own health needs they are also advocating for the wellbeing of their entire family because their health impacts the entire family. This shift in frame of reference might be empowering for many immigrant women.

CONCLUSION

A major goal of the U.S. Department of Health and Human Services is to end health care disparities among groups.³⁶ The empowerment framework, encompassing both self-advocacy and advocacy can be part of the solution. In this article, we have applied this framework to one group, immigrants with disabilities, known to be at high risk for poor health outcomes. We have discussed challenges to providing this group with health care appropriate to their needs, and also identified practical strategies for empowering them as patients. These strategies include **(a)** providing culturally sensitive services, **(b)** communicating to patients in their native language, **(c)** informing patients about ADA, IDEA and other federal and state laws that protect the rights of individuals with disabilities, **(d)** informing patients about supporting resources, and **(e)** teaching health care professionals and patients how to advocate and be assertive. Although these strategies by themselves will not end all health disparities for immigrants with disabilities, they hold promise for reducing the disparities and providing both

patients and health professionals with an important set of skills that can be applied in many health care contexts.

CONFLICT OF INTEREST

None.

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