

REPORT 7 OF THE COUNCIL ON MEDICAL SERVICE (I-11)
Patient Navigator Programs
(Reference Committee J)

EXECUTIVE SUMMARY

At the American Medical Association's (AMA) 2011 Annual Meeting, the House of Delegates adopted amended Resolution 118 (Policy D-373.997, AMA Policy Database), which asked the AMA to prepare a report for the 2011 Interim Meeting on the emerging role of patient navigators, including recommendations about appropriate training for patient navigators, and guidelines for patient navigator programs. The Board of Trustees assigned this report to the Council on Medical Service.

The following report describes the various roles patient navigators assume in the current health care environment, discusses provisions in the Patient Protection and Affordable Care Act (ACA, PL 111-148) that address patient navigators, and provides examples of training programs and ethical guidelines that influence patient advocacy work.

The concept of patient navigation evolved from a model designed to reduce health care disparities, and has expanded to include a variety of patient populations, clinical conditions and program goals. Many patient navigator or patient advocacy services today fall into one of four broad, often overlapping, categories: those focused on reducing health care disparities and increasing access to care; those focused on improving patient outcomes for a specific illness or chronic disease; those focused on streamlining care and managing cost growth; and those focused on helping patients effectively negotiate the complex web of administrative and clinical decisions associated with the current health care system.

Given the diversity of roles and responsibilities being assigned the "patient navigator" label, it is difficult to identify a single set of guidelines that is applicable in all cases. The Council believes that existing ethical principles established by patient advocacy groups provide a strong basis for ensuring that patient navigator activities enhance rather than undermine quality medical care. Specifically, it is critical that patient navigators refrain from any activity that could be construed as clinical in nature, including interpreting test results or medical symptoms, offering second opinions, or making treatment recommendations. Where appropriate, patient navigators may use clinical expertise or experience to help patients better understand information provided by their physician or other members of their medical team.

The primary role of a patient navigator should be to foster patient autonomy and to provide patients with information that enhances their ability to make appropriate health care choices or to receive medical care with an enhanced sense of confidence about risks, benefits, and responsibilities. The Council recommends a set of principles to help define the appropriate role of a patient navigator as part of a patient's health care team.

REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 7-I-11

Subject: Patient Navigator Programs

Presented by: Thomas E. Sullivan, MD, Chair

Referred to: Reference Committee J
(Barbara J. Arnold, MD, Chair)

At the American Medical Association's (AMA) 2011 Annual Meeting, the House of Delegates adopted amended Resolution 118 (Policy D-373.997, AMA Policy Database), which asked the AMA to prepare a report for the 2011 Interim Meeting on the emerging role of patient navigators, including recommendations about appropriate training for patient navigators, and guidelines for patient navigator programs. The Board of Trustees assigned this report to the Council on Medical Service. The following report describes the different roles patient navigators assume in the current health care environment, discusses provisions in the Patient Protection and Affordable Care Act (ACA, PL 111-148) that address patient navigators, provides examples of training programs and ethical guidelines that influence patient advocacy work, and recommends a set of principles to help define the appropriate role of a patient navigator as part of a patient's health care team. Finally, the Council believes that this report accomplishes the study called for in Policy D-373.997 and accordingly, recommends that the Policy be rescinded.

BACKGROUND

Broadly defined, a patient navigator is someone whose primary responsibility is to provide personalized guidance to patients as they move through the health care system. The term patient navigator is often used interchangeably with the term patient advocate, and the role may be filled formally or informally by individuals with clinical, legal, financial or administrative experience, or by someone who has personal experience facing health care-related challenges. Navigators can be employed by community groups, hospitals or insurance companies, or they may be independent consultants who offer fee-based services to people who are unwilling or unable to manage complex medical issues on their own. A patient navigator may provide assistance with specific aspects of a health care episode (e.g., researching treatment options, or appealing insurance decisions), or may offer more comprehensive services, guiding patients through the range of administrative and clinical processes associated with receiving health care services.

The concept of patient navigation has its origins in efforts to reduce health care disparities and improve health outcomes among poor and uninsured patients. In 1989, Harold P. Freeman, MD, then president of the American Cancer Society, held a series of hearings to gather information about barriers to care for underserved cancer patients. In addition to significant financial challenges, many low income patients reported communication and information obstacles, including a lack of knowledge about important health screening and maintenance activities, and how and where to access appropriate care. They also reported problems with the medical system itself, including difficulty scheduling or keeping appointments, and trouble understanding or keeping track of test results or follow up recommendations. Not surprisingly, these barriers were often compounded by emotional barriers caused by fear and frustration.

1 In response to these findings, Freeman implemented a patient navigator program in 1990 for breast
2 cancer patients at Harlem Hospital, with funding from the American Cancer Society. The goal of
3 the program was to help patients secure timely diagnosis and treatment, which helped improve
4 outcomes significantly. Through the program, patients received one-on-one support from a patient
5 navigator, who assisted with financial issues, communication barriers (e.g., low health literacy or
6 language/cultural barriers), the complexities of the medical system, psychological barriers such as
7 fear or mistrust, and practical issues such as coordinating child care or transportation.

8 9 CURRENT ROLE OF PATIENT NAVIGATORS

10
11 The concept of patient navigation has evolved beyond a model designed to reduce health care
12 disparities, and has expanded to include a variety of patient populations, clinical conditions and
13 program goals. Many patient navigator or patient advocacy services today fall into one of four
14 broad, often overlapping, categories: those focused on reducing health care disparities and
15 increasing access to care; those focused on improving patient outcomes for a specific illness or
16 chronic disease; those focused on streamlining care and managing cost growth; and those focused
17 on helping patients effectively negotiate the complex web of administrative and clinical decisions
18 associated with the current health care system.

19 20 *Reducing Health Disparities*

21
22 Consistent with the origins of the patient navigator concept, patient navigator programs targeted
23 toward reducing health disparities generally involve active outreach and patient education, and are
24 typically free to patients. Their role is to proactively help patients access appropriate medical care,
25 and to guide them through the care process to help maximize opportunities for healthy living and
26 positive medical outcomes. Patient navigators working in this capacity are likely to have
27 knowledge of local communities and resources, and have strong communication skills, and may not
28 need specific academic training or clinical expertise. Community health centers and university
29 health centers often use these types of patient navigators to expand outreach to underserved
30 populations.

31 32 *Improving Clinical Outcomes*

33
34 There is growing recognition that enhanced patient involvement and care coordination services can
35 help improve outcomes and facilitate more efficient delivery of health care services. To this end,
36 many hospitals and medical centers are using patient advocate programs to provide individual,
37 structured assistance to ensure that patients understand their medical conditions and treatment
38 options, are able to keep track of services provided in multiple settings or by multiple providers,
39 and follow through with recommended follow-up and self-management activities. Nurses or others
40 with clinical training or experience often act as patient navigators in this role. Patient navigator
41 services in this context can help ease the stress and anxiety of patients, which can be factors in
42 improved outcomes, and can help reduce the risk of gaps in care or efficiency that are associated
43 with fragmented health care delivery. As noted, the patient navigation field has its roots in cancer
44 care, and patient navigation services are a component of many cancer treatment programs. In 2012
45 The American College of Surgeons' Commission on Cancer's 2012 accreditation standards will
46 include a requirement that cancer treatment programs have a patient navigator program in place.

47 48 *Streamlining Care and Managing Cost Growth*

49
50 Some employers and health insurance companies are using patient navigators as a way of giving
51 patients access to tools and resources to help them take responsibility for and manage their own

1 health care. The goal of these programs is to ensure the judicious use of health care services,
2 which, if implemented correctly, has the potential to simultaneously improve health outcomes and
3 reduce health care costs. Employers or insurers may employ or contract with a patient navigator
4 who can offer personalized assistance to help members get the most from their health insurance
5 coverage. Services may include providing education about specific medical conditions, helping
6 patients track health care visits and organize medical records, or helping patients understand the
7 details of their health care coverage.

8 9 *Health Care Advocacy Consultants*

10
11 The administrative and clinical complexity of the current health care system leaves some patients
12 feeling vulnerable and potentially powerless to ensure they are receiving the best and most efficient
13 care available. Private health care advocates market themselves as problem solvers who can
14 minimize stress and hassle for patients. Alternatively, health care advocates may assume a more
15 protective role on behalf of the patient – using knowledge and resources to make sure that patients
16 receive the most appropriate care. Services can range from managing billing and insurance
17 processes to providing information and personalized support to help patients face complex medical
18 decisions. Patients generally pay for the services of navigators working in this capacity and work
19 with them to define the scope of services desired.

20 21 NAVIGATORS IN THE AFFORDABLE CARE ACT

22
23 Section 1311 of the ACA requires that states establish exchanges to facilitate access to health
24 insurance coverage for individuals and small businesses. Under the exchange, consumers will have
25 increased choice and increased responsibility for choosing the health care plan that best meets their
26 needs. To facilitate this process, the ACA requires that each state health insurance exchange
27 establish a “navigator program” to help individuals and businesses make informed decisions about
28 enrolling in health insurance through the exchange. The Department of Health and Human
29 Services issued a proposed rule governing the establishment of exchanges in July 2011, which
30 included guidance for the navigator program. The core responsibilities of the navigator program
31 and the types of entities eligible to serve as navigators were specified in the legislation, and
32 reflected in the proposed rule. Specifically, navigators are expected to provide expertise on
33 eligibility, enrollment and coverage details for each plan; provide information in a fair, accurate
34 and impartial manner; facilitate the enrollment process; and provide referrals for conflict resolution
35 services for enrollees with complaints or concerns. Eligible entities include community groups,
36 trade or professional associations, chambers of commerce, and licensed agents or brokers.
37 Notably, health insurers and their representatives are not eligible to participate in the navigator
38 program. The proposed regulation specifies that navigators must comply with licensing,
39 credentialing or other standards that may be established by the state or the exchange, but does not
40 propose any uniform standards or requirements.

41
42 Section 3510 of the ACA extends the length of the Patient Navigator Outreach and Chronic
43 Disease Prevention Program, which was established under the Bush Administration to provide
44 grants for the establishment of patient navigator programs to reduce barriers to care and improve
45 health care outcomes. Public and non-profit health centers, health care facilities, or non-profit
46 entities were eligible to apply for grants, which were previously authorized through 2011. The
47 ACA extends the grant program through 2015; however, funds have not been appropriated for this
48 provision of the law.

PATIENT NAVIGATOR TRAINING PROGRAMS AND STANDARDS

The skills and qualifications necessary to be an effective patient navigator vary greatly based on the role the navigator is trying to fill. Navigators helping patients understand medical conditions and coordinate care need more formal clinical expertise than navigators helping patients identify medical resources in their communities. Similarly, legal or financial backgrounds may be useful for navigators assisting with insurance paperwork or claim disputes, whereas navigators helping people manage the emotional aspects of the complex health care system may benefit from having training or experience as social workers or community organizers.

Although there are no formal training requirements associated with patient advocacy work, several entities offer certificates or continuing education programs in patient navigation or patient advocacy. For example, the Patient Navigation Program at the Harold P. Freeman Institute is a three day program for individuals providing patient navigator services within the context of an organization (e.g., a hospital or community center). Using cancer care as a case study, the program helps participants understand how to use patient navigation to improve diagnostic and treatment success rates among patient populations, and how to use patient navigation to improve organizational efficiency overall. The program materials note that while individuals with many different levels of education and experience can serve as patient navigators, the specific functions assigned to patient navigators should be consistent with their level of experience and training.

The Society for Healthcare Consumer Advocacy (SHCA) is part of the American Hospital Association, and the majority of its members are affiliated with hospitals or health care systems. SHCA offers a web-based certificate program for individuals working as patient advocates or those interested in learning more about the field. The program contains 14 modules covering issues related to patient advocacy, health care management, communications, data analysis and customer service. Continuing education credits are available for professional students completing the certificate program.

The Colorado Patient Navigator Training Program offers two programs in partnership with the University of Colorado Cancer Center, Denver Health (which serves medically underserved patients) and the Colorado Community College system. The Level 1 track offers basic training for community health workers or others interested in helping connect patients with health care services. Courses include basic patient navigation training skills, identifying patient resources, and basic health promotion. Level 2 training is intended for nurses, social workers, and others with academic degrees and more experience in the health care field. Courses for the Level 2 program focus on care management, patient coaching, and physical aspects of disease.

Some schools offer patient advocacy training in conjunction with other academic programs. The Center for Patient Partnerships is affiliated with the University of Wisconsin Schools of Law, Medicine and Public Health, Nursing and Pharmacy, and offers a Consumer Health Advocacy Certificate to students enrolled in these schools. Sarah Lawrence College in New York was the first school to offer a master's degree in health advocacy, designed to prepare students for a wide range of health care advocacy roles. The program includes course work in physiology, history, law, economics, health policy and ethics, and students are required to complete three fieldwork assignments in a relevant practice-based setting.

Ethical Standards for Patient Advocacy

The National Association of Health Care Advocacy Consultants (NAHAC) is a professional group serving more than 190 individuals working in the field of health care advocacy, many of whom are

1 affiliated with private health care advocacy consulting groups. The organization is involved in
2 ongoing efforts to develop and identify best practices for the industry and requires that its members
3 adhere to a code of ethics that encompasses seven guiding principles: transparency and honest
4 disclosure regarding fees, training, experience, and possible conflicts of interest; protecting
5 confidentiality and privacy; fostering autonomy; provision of competent services; avoidance of
6 impropriety and maintenance of professional boundaries; avoidance of discriminatory practices;
7 and continued learning (www.hanac.com/code/). The Code explicitly states that health care
8 advocates should not be involved in direct medical care of any kind.

9
10 SHCA members also commit to a code of ethics, embodying many of the same principles
11 expressed in the NAHAC code. The SHCA code emphasizes that advocates have a primary
12 responsibility to the patient, and should not use their position to exert undue influence on the
13 patient. Like NAHAC's code, SHCA emphasizes the importance of providing objective
14 information to patients, and promoting autonomy in patient decision-making.

15 16 RELEVANT AMA POLICY

17
18 The AMA has extensive policy related to individuals who work with patients as part of a health
19 care team. Several policies reinforce the concept of physicians bearing the ultimate responsibility
20 for patient care, and advocate that allied health professionals such as nurses or physician assistants
21 function under the direct supervision of a physician (e.g., H-35.970, H-35.973, and H-35.989).
22 Policy H-35.978 encourages hospital medical staffs to establish a process for physicians to provide
23 input for and review of educational programs operated by the hospital for patients. Policy
24 H-160.938 promotes a physician-led, team approach to disease-specific patient care and self-
25 management programs. Policy H-35.996 states that hospital medical staffs should have the
26 authority to determine what functions and services should be made available for patient care by
27 members of "emerging or expanding health professions."

28 29 DISCUSSION

30
31 The general concept of patient navigation is in many ways consistent with the concept of the
32 patient-centered medical home, which emphasizes physician-led care that is coordinated and
33 integrated across all elements of the health care system and the patient's community (see Policy
34 H-160.919). Services that can increase patient access, help improve health outcomes, help patients
35 understand and manage their health conditions and treatment options, and ease patient stress can
36 facilitate improved patient care and even enhance the patient-physician relationship. Conversely,
37 to the extent that patient navigation services have the potential to restrict or limit access to care, or
38 interfere with the patient-physician relationship by delaying or contradicting treatment plans, it is
39 important that our AMA be prepared to challenge the intrusion of such practices.

40
41 Given the diversity of roles and responsibilities being assigned the "patient navigator" label, it is
42 difficult to identify a single set of guidelines that is applicable in all cases. The Council believes
43 that the ethical principles established by the NAHCA and SHCA provide a strong basis for
44 ensuring that patient navigator activities enhance rather than undermine quality medical care.
45 Specifically, it is critical that patient navigators refrain from any activity that could be construed as
46 clinical in nature, including interpreting test results or medical symptoms, offering second
47 opinions, or making treatment recommendations. Where appropriate, patient navigators may use
48 clinical expertise or experience to help patients better understand information provided by their
49 physician or other members of their medical team.

The Council also agrees with NAHAC and SHCA that the primary role of a patient navigator should be to foster patient autonomy, and to provide patients with information that enhances their ability to make appropriate health care choices, or to receive medical care with an enhanced sense of confidence about risks, benefits, and responsibilities. To the extent that navigators are helping patients make decisions about their medical care (e.g., understanding treatment options presented by their physician), procedures should be in place to ensure direct communication between the navigator and the patient's medical team.

NAHAC ethical standards call for transparency and full disclosure of the advocate's training, experience, and credentials, which can help patients evaluate whether the navigator is qualified to perform the services he or she is offering. Patient navigators can guide individuals through many pieces of the health care system, and full disclosure of training and experience allows patients to determine which services the individual is qualified to provide.

NAHAC standards also require full disclosure of potential conflicts of interest, including employment arrangements, and prohibit advocates from accepting remuneration for making referrals, and from steering clients toward resources from which the advocate might benefit financially. Although advocates employed by hospitals or health care systems are understood to be representatives of those institutions, patients should never be pressured to choose a specific health care provider and should have the freedom to seek care from another facility.

RECOMMENDATIONS

The Council on Medical Services recommends that the following be adopted and that the remainder of the report be filed:

1. That our American Medical Association recognize the increasing use of patient navigator and patient advocacy services to help improve access to care and help patients manage complex aspects of the health care system. In order to ensure that patient navigator services enhance the delivery of high-quality patient care, our AMA supports the following guidelines for patient navigator programs:
 - a) The primary role of a patient navigator should be to foster patient empowerment, and to provide patients with information that enhances their ability to make appropriate health care choices and to receive medical care with an enhanced sense of confidence about risks, benefits, and responsibilities.
 - b) Patient navigator programs should establish procedures to ensure direct communication between the navigator and the patient's medical team.
 - c) Patient navigators should refrain from any activity that could be construed as clinical in nature, including interpreting test results or medical symptoms, offering second opinions, or making treatment recommendations. Patient navigators should provide a supportive role for patients and, when necessary, help them understand medical information provided by physicians and other members of their medical care team.
 - d) Patient navigators should fully disclose relevant training, experience, and credentials, in order to help patients understand the scope of services the navigator is qualified to provide.

- 1 e) Patient navigators should fully disclose potential conflicts of interest to those whom
2 they serve, including employment arrangements. (New HOD Policy)
3
- 4 2. That our AMA work with the American College of Surgeons and other entities and
5 organizations to ensure that patient navigators are free of bias, do not have any role in
6 directing referrals, do not usurp the physician's role and responsibility for patient education
7 or treatment planning, and act under the direction of the physician or physicians primarily
8 responsible for each patient's care. (Directive to Take Action)
9
- 10 3. That our AMA rescind Policy D-373.997. (Rescind HOD Policy)

Fiscal Note: Staff cost estimated at less than \$500.

References for this report are available from the AMA Division of Socioeconomic Policy Development.