The Massachusetts Care Coordination Program:

A Mixed Methods Evaluation

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Executive Summary

Literature Review

- Community-based patient navigators provide an important means for effective delivery of health care services to underserved populations that are ethnically, culturally, and linguistically diverse.
- Patient navigators guide cancer patients "through the healthcare system by assisting with access issues, developing relationships with service providers, and tracking interventions and outcomes" (Steinberg 2006).
- Most but not all quantitative studies have identified positive effects of navigation programs on patient access and satisfaction. Limited qualitative research suggests that patients value navigation both for instrumental support in making connections in the health care system and for emotional support during episodes of illness.
- Prior research suggests positive effects of case management on patient satisfaction and functioning, and on the costs of care.

- Patients in the former Massachusetts Women's Health Network were very satisfied with case management services. Satisfaction with WHN case management services seemed to vary among Hispanics in relation to length of time in the United States, with more recent immigrants being more satisfied.
- Care coordination is a response to patients' experience of the health care system as fragmented and as neglecting the interconnections between different illnesses and disease processes.
- Some research has identified benefits of care coordination for health outcomes with serious mental illness, heart disease, stroke and diabetes, but insufficient research has been conducted to confirm positive effects of coordinated care on cancer patients' outcomes and randomized trials have identified few effects on adherence and quality of care.
- No particular care coordination strategy has been identified as preferable.
- The emphases on coordinated care and on patient navigation may not always be complementary.

Staff interviews

- In-person interviews were conducted with almost all Patient Navigators, Case Managers, and Program Directors employed by the Care Coordination program at 17 program health care centers.
- The Care Coordination Program encouraged program health care centers to develop a more holistic, team-based approach to health care. At some sites this approach was

adopted throughout the center, at others it only characterized the program itself, and in some it had only partially been implemented.

- There were some implementation problems at some centers, with staff who complained that others were unaware of the Care Coordination program focus or the responsibilities of program staff.
- The social backgrounds of Care Coordination patient navigators differed markedly from those of case managers, with many reflecting the ethnic and educational backgrounds of the communities in which their patients live.
- On-the-job training was a key to effective preparation for Care Coordination work. Patient navigators assessed favorably the centralized DPH training, but found it was not sufficient preparation for specific work tasks. Some recommended a more participatory approach to quarterly statewide meetings, so that staff could share experiences. Case managers tended to feel less well prepared for their specific program responsibilities.
- Much of the work of patient navigators and case managers was carried out on the phone, from contacting patients to making appointments. Both groups, but particularly patient navigators, worked in multiple roles and maintained high caseloads.
- According to staff, many patients worked multiple jobs and had family pressures and concerns about their status as immigrants that interfered with engagement in health care.
- Staff reported more difficulty in providing services to patients with mental illness or multiple ailments compared to those who only had single physical illnesses.
- Numerous case managers engaged in the same type of efforts to help patients overcome psychosocial and practical barriers to health care, which were central duties of patient navigators

- Unmet psychosocial needs presented challenges for both patient navigators and case managers, but were more often rated as a problem by case managers.
- Cultural beliefs often interfered with prevention and other forms of proactive involvement of patients in maintaining their health. Patient navigators were often able to discuss such beliefs with patients in ways that led to healthier decisions.
- Case managers often had to help patients overcome fears about cancer test results.
- Practical problems often interfered with effective health care, with employment and transportation problems often proving most difficult. Patient navigators were often able to lessen these barriers.
- Literacy was a major problem in ensuring patient adherence to treatment plans.
- Patient enrollment and followup most often occurred on the phone. This hindered the development of meaningful personal relations, although some phone-based relations with patients were very meaningful.
- Patient navigators tended to be more satisfied with the management of the Care Coordination program than were case managers.
- Job satisfaction was higher among patient navigators than among case managers, except in terms of pay and relations with other agencies.

Patient interviews

- A random sample of 383 Care Coordination patients was surveyed by phone. Although almost all (90%) of those contacted who were aware of the program agreed to an interview, difficulties in reaching eligible patients led to an overall survey response rate of 52%.

- Thirty phone survey respondents were also interviewed in person. There were no detectable differences in characteristics or orientations between those interviewed in person and the other phone survey respondents.
- Most Care Coordination Program patients surveyed were women (85%), with a relatively low level of education (only 19% with a college degree) and half who were not employed. Their average (mean) age was 53.
- About one-third were currently married. Two-thirds of the women lived with dependent children, while three-quarters of the men did not live with children.
- About half were Hispanic, more than half were born outside of the U.S., and three-fourths were in first-, second-, or third-generation immigrant families.
- Many of the first-generation immigrants preferred to speak in Spanish or Portuguese.
- About one-third of the patients who used interpreters reported difficulties in communicating with health care providers. Patients who spoke Portuguese were less likely than those who spoke Spanish to be able to communicate with their health care providers in their own language, so they were more likely to use interpreters.
- Hispanics, immigrants, and those who did not speak English in the interview tended to have less education and more dependent children than others. Portuguese speakers were less likely to be working than English speakers, while Spanish speakers were more likely to be working.
- Patients rated their own health as relatively poor, although more felt their health had improved in the past year than felt it had worsened. The average number of specific health problems reported was three. Hypertension, depression, and dental concerns were the most common specific health problems.

- Some health indicators varied with ethnicity, language, and/or immigration status. Hispanics, Portuguese speakers, and those who rated themselves as less capable in English assessed their health as poorer than others.
- With respect to specific health problems, immigrants reported lower rates of asthma, depression, substance abuse, and less smoking than did non-immigrants; some of these health advantages also appeared when Hispanics, Spanish speakers, and/or Portuguese speakers were compared to whites or English speakers.
- African American respondents were more likely to report asthma than white respondents, while white respondents, non-immigrants, and English speakers were all more likely to be depressed.
- Four in every five respondents had received at least one health service in the preceding year, with dental services being the most common and use of emergency services also being frequent.
- Most of those who reported a specific health problem had not received a service specifically for that problem. The exceptions were substance abuse and dental problems, for which at least three-quarters reported treatment.
- The health problems associated with the highest rates of ER use were CVD, asthma, and substance use, while the rate of hospitalization was elevated for those with CVD and substance abuse.
- Patients in program sites that were hospital-affiliated were much more likely to have been hospitalized or to have used emergency services in the past year
- Most respondents were unaware of having been helped by a patient navigator, even when they were read the names of patient navigators in their clinic. Patients with cancer

concerns and diabetes were more likely to be aware of having had a patient navigator and those who were depressed were in more frequent with their patient navigator than others.

- Those who were aware of having had contact with a patient navigator reported a range of services, with help scheduling appointments being the most common form of assistance and transportation assistance being the least.
- Contact with case managers was also uncommon among the patient sample as a whole, with it most likely to have occurred with patients having had cancer concerns.
- Patients with case managers were more likely to have been hospitalized or to have used emergency services in the past year, while those who were aware of having a patient navigator were more likely to have used "other" health services.
- Patients who felt they had been depressed in the past year reported having spoken with their patient navigator much more often than did those who had not been depressed.
- Hispanics were less likely to recognize the name of a patient navigator, as were immigrants and those who spoke Spanish or Portuguese. However, Spanish and Portuguese speakers were more likely to have been assigned a case manager than English speakers.
- Care Coordination patients were very satisfied with their health care experiences at the clinics from which they received their health care and rated specific services received and the apparent level of care coordination highly.
- Ratings of followup, of help with transportation, and of apparent communication with other health providers were somewhat lower, but still largely positive.
- In spite of these high ratings, respondents reported some barriers to receipt of health care as particularly problematic, including concerns about costs and fear of bad news.

- Those who were Hispanic, first generation immigrants, and who had difficulties communicating in English were somewhat less satisfied with some aspects of their health care experience, but those who were interviewed in Spanish or, most markedly, in Portuguese tended to be more satisfied.
- Higher levels of education and perceiving more health barriers were associated with less satisfaction.
- Recognition of having a patient navigator or case manager was associated positively with only a few aspects of service satisfaction. One key difference was that among those whose primary language was not English, those who recognized a patient navigator reported fewer communication problems.
- Those assigned a case manager were more satisfied that staff kept in touch about their health needs.
- In-person interviews with 30 patients confirmed high rates of satisfaction with health care experiences.
- Patients at most sites reported similar levels of satisfaction; there was limited variation in satisfaction indicators between some sites involving particular ethnic groups.

Recommendations

- Ensure some time for patient navigators to visit patients in the community, to meet with patients in person, and/or to attend health fairs and other community events.
- Expect a team approach to program delivery at each center, with regular team meetings and case reviews.

- Expect center meetings and regular email blasts to publicize the Care Coordination program and ensure understanding by all staff of the roles of patient navigators and case managers.
- Provide training for case managers focused specifically on Care Coordination responsibilities and roles.
- Include some joint training sessions with patient navigators, risk reduction educators, and case managers.
- Enhance transportation assistance through program linkages and funding.
- Improve followup after patient visits and to encourage patient participation in relevant community programs.
- Add more forms of language assistance for Portuguese speakers and encourage recruitment of more Portuguese-speaking staff.
- Provide options within the program for dental care.
- Use a more proactive approach to engage patients with unmet health needs in the specific health services they require.
- Enhance the availability of mental health services for those with depression.
- Develop guidelines and encourage coordination of on-the-job training for program staff.
- Schedule regular meetings for staff exchange about best practices and case histories.
- Develop strategies that give case managers greater time for their Care Coordiantion work.
- Create a greater sense of program engagement by case managers through team meetings, focused training, and opportunities to share responsibilities for patients.
- Maintain a record of all contacts of patients with patient navigators and case managers as part of patients' medical records.

- Add chronic disease indicators and related services as required fields in the program database.

The Massachusetts Department of Public Health began the Care Coordination Program (CCP) in 2006 in order to improve identification of health needs among low income uninsured and underinsured residents and to increase the effectiveness of health services for this population. The MA CCP added two new elements to the case management services formerly delivered by the Women's Health Network and the Men's Health Program: navigation services to guide patients in the health care system and coordinated care to address most efficiently multiple health needs.

This report presents the findings of a two-year evaluation of the Care Coordination Program. It begins with a brief program description and an extensive review of prior research on the major elements of the CCP—patient navigation, case management, care coordination, and patient satisfaction—and on a central outcome in the evaluation: patient satisfaction. Evaluation findings are then presented separately for the two major elements of the research, staff interviews and patient interviews, with particular attention to staff work roles, patient health care barriers, the impact of ethnicity, immigration status, and language, and the level of patient satisfaction. Cancer screening data for program participants are presented in a separate section.

Program Background

Congress funded the National Breast and Cervical Cancer Early Detection Program (Breast and Cervical Cancer Mortality Prevention Act of 1990) to improve the rate of screening, testing, and referral to treatment for low income uninsured and underinsured women at risk of breast and cervical cancer (NBCCEDP 1990). As implemented by the U.S. Centers for Disease Control, the NBCCEDP requires all states, tribes and territories to employ case managers to engage eligible individuals in screening, followup testing and, as needed, referral to treatment, but many program details are at the discretion of the states. The same legislation initiated the

WISEWOMAN program—**W**ell–**I**ntegrated **S**creening and **E**valuation for **Wom**en **A**cross the **N**ation—to enhance screening and education services for those at risk of CVD and many states have added this program to their NBCCEDP program. In 2000, the Breast and Cervical Cancer Prevention and Treatment Act provided for payment of treatment services so that women identified through the NBCCEDP as having breast and cervical cancer would be able to obtain treatment for it.

Since its inception, the NBCCEDP has served more than 3.7 million women (NBCCEDP 1990). In Massachusetts, the Women's Health Network has been successful in meeting the needs of many low income women for screening and followup in a way that both clients and staff have reported as very satisfactory (Schutt et al. 2008; Schutt et al. 2010). An expert panel sponsored by the Department of Public Health in 2005 and led by Professor Russell Schutt (Estabrook et al. 2008) recommended development of a patient navigation program in order to improve client enrollment and retention and an integrated service model to facilitate coordinated care for multiple health problems. The DPH adopted these recommendations and it is these two new program elements—patient navigation and coordinated care—that are to be evaluated.

Research Background

Disparities in Health and Health Care

Disparities in both health and health care have been described in numerous studies of cancer and other diseases and across groups distinguished by race, ethnicity and social class (Shavers and Brown, 2002; Shinagawa, 2000). These disparities are not consistent between the diseases and groups that are compared, they vary over time, and they may belie the complexities of within-group variation and the effects of individual-level characteristics and of regional and national contexts. Nonetheless, disparities in health and health care represent a major impediment to improving population health and thus pose a great challenge for the health care delivery system.

Disparities in Illness

Compared to white women, black women have much higher rates of cervical cancer (at older ages), more aggressive breast tumors at earlier stages and present at a more advanced stage of breast carcinoma (Royak-Schaler and Rose, 2002; Tang et al. 1999). As a result, black women with cancer have higher rates of mortality and other adverse outcomes (Newman et al., 2002); by contrast, Hispanic women have rates of survival similar to those for white women (Funch 1987). Race itself predicts stage of diagnosis for both breast and prostate cancer independent of socioeconomic status (Baquet and Commiskey, 2000; Hoffman-Goetz, Breen and Meissner 1998; Schwartz et al., 2003).

Lower income is associated with more advanced stage distributions of and mortality from breast cancer (Baquet and Commiskey, 2000; Funch, 1987; Schwartz et al., 2003). Overall, there has also been a strong negative association between SES and the incidence, mortality, and stage at diagnosis of cervical cancer in the U.S. (Hayward et al. 1988; Singh et al. 2004).

Risk factors for cardiovascular disease, including hypertension, are more prevalent among black as compared to white Americans and are also linked to lower SES—and these differences persist even when treatment is equated (Sharma et al., 2004; Sheats et al., 2005). CVD risks tend, in contrast, to be less common among Hispanics and Alaskan Natives (Finkelstein et al. 2004), but one study indicates that Mexican Americans, at least, lose this comparative advantage at higher SES levels (Sharma et al., 2004).

Disease risks vary with age, and so age must be taken into account when predicting health risks as well when attempting to identify the independent influence of other demographic characteristics like race and ethnicity.

Disparities in Services and Behavior

Disparities have also been documented repeatedly in service delivery and health care behavior, although these differences reflect no simple or single pattern. Some have even concluded that screening behavior does not vary in relation to demographic characteristics (Burnett, Steakley and Tefft 1995), but other studies have provided more evidence of ethnic and racial differences in screening.

Several studies find that Latina women have lower rates of mammography screening than white women, but Latinas do not differ from whites in rates of cervical cancer screening or clinical breast exams and even the mammography screening disparity does not occur in all areas (Abraido-Lanza, Chao and Gammon 2004; Borders et al. 2003; Fernandez and Morales, 2007). Both the National Health Interview Survey (1991) results (Abraido-Lanza, Chao and Gammon 2004) and those obtained by Fernandez and Morales (2007) indicated that lower rates of screening among Latinas compared to non-Latina whites were entirely explained by socioeconomic factors. Schootman et al. (2003) found that women who had health insurance were more likely to get mammography and cancer screenings as opposed to those who didn’t have health insurance, but apart from these differences in insurance, race and ethnicity had little effect on mammograms and cancer screenings (see also Fernandez and Morales, 2007). By contrast, analysis of data collected in the 1998 National Health Interview Study revealed that covariates do not explain the disparity in screening rates between Hispanics and whites, although they do explain disparities between blacks and whites (Rao et al. 2004). In the Bay Area, screening rates are much lower for non-English speaking Latinas and Chinese women than for whites and other English speakers (Hiatt et al. 2001).

Like ethnic disparities, racial disparities have not been found consistently. Asian American women have less awareness about cancer and lower screening rates, although these differences appear to vary between ethnic subgroups, as well as with insurance, income, and usual care provisions (Chen et al., 2004; Kagawa-Singer and Pourat, 2000; Lee-Lin and Menon, 2005). Non-white women in Colorado were less likely to adhere to screening recommendations than white women (Strzelczyk and Dignan 2002). The racial and ethnic disparities in screening that have been identified are not explained by correlated differences in health care access and satisfaction (Somkin et al. 2004). However, black and white women report similar mammography rates, and at least one study in Missouri found higher rates of compliance with cervical cancer screening recommendations among black women (Ackerman et al. 1992; Simoes et al. 1999).

Lower economic status, including lacking insurance, is associated with less adequate screening (Coughlin and Uhler 2002; de Bocanegra et al. 2009; Hoffman-Goetz, Breen and Meissner 1998; Hsia et al. 2000; Otero-Sabogal et al., 2003; Pearlman et al. 1999; Pearlman, Rakowski and Ehrich 1996; Simoes et al. 1999; Strzelczyk and Dignan 2002). At least in Ontario Canada, SES disparities in screening persisted even under a universal health care system (Katz and Hofer 1994; Katz, Zemencuk and Hofer 2000). Among Missouri women, the rate of Pap smears is inversely associated with income (Ackerman et al. 1992). Nonetheless, although the rate of screening rises with SES, removing economic barriers did not increase screening among rural women when such other barriers as knowledge, attitudes, and access persisted (Lantz, Weigers and House 1997).

Health care access is often directly related to economic status and health care insurance, but whatever its source, it influences screening behavior. Not having a usual source of care explained much of the lower screening rates of Hispanics and black women compared to whites (Corbie-Smith et al. 2002). In the U.S., women in rural areas have lower rates of screening access compared to women in urban areas (Coughlin et al. 2002). Poorer healthcare experiences are associated with less likelihood of screening for breast cancer (Borders et al. 2003).

Age is also related to screening rates and other health behaviors. Likelihood of screening declines with age among both Hispanics (Hayward et al. 1988) and blacks (Hoffman-Goetz, Breen and Meissner 1998; Simoes et al. 2004; but see Strzelczyk and Dignan 2002). Age also alters the effects of other predictors of screening: women who are younger than 65 are less likely to have cancer screening if they lack health insurance or have fee-for-service insurance, while women who are 65 or older are less likely to be screened if their only health insurance is Medicare (Hsia et al. 2000).

Knowledge of cancer risk factors is associated with screening intentions and having had more recent screening (Nguyen and Kagawa-Singer 2008; Pearlman et al. 1999; Pearlman, Rakowski and Ehrich 1996) and more education is associated independently with a greater likelihood of screening (Strzelczyk and Dignan 2002; Hsia et al. 2000; Pearlman et al. 1999; Pearlman, Rakowski and Ehrich 1996).

Women also report a variety of barriers to screening related to the behavior of health care staff and their own orientations and situations (Funch 1986; Gelberg et al. 2000; Hsia et al. 2000). The Women's Health Initiative Observational Study highlighted the importance of having a usual care provider and maintaining contact with that provider, as well as demographic factors (Hsia et al. 2000; see also Abraido-Lanza, Chao and Gammon 2004; Clark et al. 2009).

Nguyen and Kagawa-Singer (2008) were told that women were less likely to participate in screening due to not having adequate assistance to navigate the health care system, lacking professionally trained health care interpreters and translators, and lacking a regular source of culturally competent care, as well as lacking health insurance or affordable health care, lacking time for health care because of employment and/or family obligations, and lacking transportation and child care. Women in DC were less likely to seek screening if they had had uncaring healthcare professionals or were not encouraged by significant others in their lives, and also if they had not previously maintained regular screening practices (Burnett, Steakley and Tefft 1995). Women in Texas (Bobo et al. 1999) reported that they were less likely to engage in breast cancer screening due to fear of radiation, anxiety about false negatives and true positives, and embarrassment, pain and discomfort in previous mammograms (Bobo et al. 1999). Mistrust of medical professionals' willingness to treat members of their ethnic group fairly is associated with less screening among black and Latina urban women (Thompson et al. 2004).

Physicians are themselves sensitive to some of the factors that influence patients, and so are less likely to adhere to breast cancer screening guidelines if there are cost concerns for patients or high levels of patient worry and refusal to participate. Physicians who worry more about radiation risks and who lack confidence in performing a clinical breast exam are also less likely to engage in screening (Ackermann and Cheal 1994).

Disparities in Communication

Good communication is necessary for health providers to obtain accurate patient information as well as to provide adequate treatment and preventive information, and thus to improve patient satisfaction and health outcomes (Bredart et al. 2005; Clemans-Cope and Genevieve 2007; DiMatteo and Hays 1980; Eyigor et al. 2009; Jackson et al. 2001; Williams and

Calnan 1991). Low health literacy is associated with poorer screening and other disease prevention behaviors (Lindau et al. 2001), and yet at least one study reveals that many screening materials for blacks are not written at an appropriate reading level (Guidry, Fagan and Walker 1998). Patients with less education tend to be less satisfied with health care providers because they are more likely to feel that the information they provided was not understood or that the provider didn't pay enough attention (Clemans-Cope and Genevieve, 2007). Less education is associated consistently with poorer rates of screening, across different racial and ethnic groups (Coughlin and Uhler 2002; Hoffman-Goetz, Breen and Meissner 1998; Hsia et al. 2000; Pearlman et al. 1999; Pearlman, Rakowski and Ehrich 1996; Simoes et al. 1999; Strzelczyk and Dignan 2002).

Communication problems are common when services are provided to LEP patients. Bakemeier et al. 1995) found that only 58% of Colorado nurses were able to provide screening information in Spanish, compared to 90% who could do so in English. LEP patients report not asking questions about health concerns, not being listened to by health care providers, and not understanding what their doctor tells them (Clemans-Cope and Genevieve, 2007). Many Hispanics feel discriminated against when they must wait while an interpreter is located and perceive health care providers as becoming impatient when they don't understand what the patient is telling them (Thiel de Bocanegra, et al. 2009). They also dislike talking to a recording when they call a health center and feel they need a Spanish speaker on the phone in order to understand the information they are given (Watkins Davis et al., 2009).

Poor communication is a particularly important barrier to adequate health care for limited English proficiency (LEP) patients, particularly immigrants, resulting in medical errors, misdiagnosis and poor care quality (Carter-Pokras et al., 2004; de Bocanegra et al. 2009; Ku and

Flores, 2005). LEP patients are less likely to have screenings, mammography or other preventive tests, they lack access to health information through the Internet, and they are less likely to have health insurance and to receive continuity of care (Austin et al. 2002; Garbers et al. 2009; Jacobs et al., 2005; Lobell et al. 1998). Communication problems also create patient security and confidentiality issues and low satisfaction, and so can lead to lawsuits and hospital sanctions (Johansson et al. 2002; Ku and Flores, 2005; Hawley et al. 2010; Ware and Davies 1983; but see Cleary 1988).

The connection between communication issues and feelings of dissatisfaction has been highlighted in research that takes English proficiency into account. Low health literacy is associated with dissatisfaction and regret about breast cancer treatment decisions, and taking account of health literacy differences partially explains more dissatisfaction about decisions among Latina women (Hawley et al. 2008). In the Bay Area, screening rates are much lower for non-English speaking Latinas and Chinese women than for those who speak English (Hiatt et al., 2001). Spanish-speaking Latino patients on the West Coast were significantly less satisfied with health care providers than English speakers, whether Latino or Anglo (Morales et al., 1999). Hispanic women who use English more also express more of a preference for participating actively in health care decision-making and information seeking (Tortolero et al., 2006).

In spite of the evident value of improving communication with health care providers, translation services are often deficient. People providing communication and translation services are often poorly trained and inexperienced (Ku and Flores, 2005). Many Hispanics report that they have to bring children to their health care appointments to act as interpreters (Thiel de Bocanegra, et al. 2009). Medicare often doesn’t pay for translation services, even though an interpreter adds only.5% ($4.04) to the average patient visit cost (Ku and Flores, 2005); some states pay interpreter services through Medicaid and other states allow reimbursement for interpreter services. Insurers typically do not pay for interpreters (Ku and Flores 2005). Among health care providers in Colorado, Bakemeier et al. (1995) found that neighborhood healthcare centers were more likely to provide services in Spanish than private institutions.

Cultural Beliefs

The health beliefs associated with different ethnic groups' cultures also influence orientations to health and behaviors regarding health care, including mammography screening patterns (Ellmer and Olbrisch, 1983; Kudadjie-Gyamfi and Magai 2008). Considerable research indicates that North Americans and Europeans persons tend to share an individualist orientation, while Latin Americana, Africans, and Asians—and those who have migrated from those continents without assimilating to North American culture—tend to be more collectivist (Ting-Toomey et al. 2000). A mismatch between the level of involvement in healthcare decision-making that is desired and experienced is associated with less patient satisfaction, and, although most patients wish to have an active role in decision-making (Bouleue et al. 20010), these desires vary across ethnic groups (Hawley et al. 2008).

Hispanics. Hispanic women suffer more from breast and cervical cancer and are more likely to die from these diseases in part because they engage less in screening and mammography (Jacobs et al., 2005; Watkins Davis et al., 2009). Cultural beliefs may explain in part this lower level of engagement in preventive behaviors (Thiel de Bocanegra et al., 2009). Hispanics tend to avoid conflict, seeking instead to be cooperative, and as a result may be reluctant to ask questions or even engage in a medical dialogue with a health care provider or physician (Lobell et al., 1998). Hispanic women with a strong ethnic identity as Hispanics may distrust expert information delivered by Anglos (Oetzel et al., 2007). Hispanic women tend to have stronger interpersonal relationships, and so prefer to receive information through face-to-face channels (Oetzel et al., 2007). Another cultural belief that may affect preventive behavior is a willingness to leave things up to God, even though attending church is itself associated with cancer screening maintenance among Latinas (Otero-Sabogal et al., 2003). Among some Hispanics, “fatalismo”—an outlook that life events are inevitable—diminishes interest in screening, and so Latinas who have less fatalistic attitudes are more likely to maintain cancer screening (Austin et al., 2002; Bakemeier et al., 1995; Oetzel et al. 2007; Otero-Sabogal et al., 2003). Research also indicates reluctance among Hispanic women to be examined by a male physician, misplaced confidence that cancer will not be a problem for them, fear of the exam results and lack of flexibility in scheduling an appointment (Austin et al. 2002; Bakemeier et al., 1995; Lobell et al., 1998; Stromborg et al., 1998; Thiel de Bocanegra et al., 2009).

The salience of these cultural beliefs varies between patients and locations. Patients with a bicultural identity have more communication possibilities and skills and so interact more easily with members of both cultures (Oetzel et al. 2007). Latina women with breast cancer in Los Angeles, especially those who prefer to speak Spanish, were less satisfied with their treatment decision-making experience with medical providers (Hawley et al. 2008). Hispanic patients were more satisfied with their health care when they had Hispanic rather than non-Hispanic physicians (as was also true for black patients with black physicians) (Saha et al., 1999). Nurses who worked at health care centers in Colorado with more than one-third Hispanic patients reported more problems with transportation, childcare, and work releases than nurses from private practices (Bakemeier et al. 1995). Satisfaction among Hispanic women in the Massachusetts NBCCEDP program varied with preference for speaking Spanish, possibly related to level of assimilation; as predicted by segmented assimilation theory, women who preferred to speak English, and so were more likely to compare their health care to that of others in the U.S. rather than to those in their country of origin, were less satisified (Schutt, Cruz and Woodford, 2008).

Concern by partners about their spouses' health seems to compensate for some of the obstacles Hispanics face in receiving health care (de Bocanegra et al. 2009). One investigation indicates that partners help each other according to their needs, with the men either going with their wives to appointments or taking care of the children while their spouse goes to appointments (Thiel de Bocanegra, et al. 2009). Social support from others may also help some Hispanic women to overcome barriers to receipt of health care (Dias Ribeiro de Paula Lima, et al. 2005).

Russians. Language barriers are high for LEP Russian speakers; even in the San Francisco area there is little information on cancer translated into Russian and few trained translators able to work with Russian families and patients. In addition, Russian patients who are diagnosed with cancer tend to believe they have been given a death sentence, thus creating a cultural barrier to honest communication. One study suggests that Russians tend to be demanding in their interactions with each other and with health care providers, potentially diminishing the quality of health care experiences (Dohan and Levintova 2007).

Asian Americans and Pacific Islanders. The category of Asian American and Pacific Islanders represents a heterogeneous mix of languages, cultures and beliefs, but screening for cancer is uncommon among Chinese, Japanese and Vietnamese women (Lee-Lin and Menon 2005). Access and acculturation both influence screening disparities among Asian American women, but in different ways among Chinese, Filipino, Japanese, and South Asian women (Pourat et al. 2010). Jacobs et al. (2005) found that Chinese, and Japanese women, as well as those who were Hispanic were more likely to report preventive test practices for breast and cervical cancer if they were fluent in English than if they were not. Lee-Lin and Menon's (2005) review of the literature indicated that Chinese Americans perceive fluency in English, education, health insurance coverage and knowledge as barriers to mammography, while they perceive recommendations by physicians and nurses, early detection, and acculturation as facilitating factors. Vietnamese report lack of health insurance and low knowledge as barriers for screenings or Pap smears, while Japanese consider the strongest barriers to adopting cancer prevention practices to be language, cost and fear. Screening behavior was better among Asian American women who communicated with their mothers, were open about sexuality, had a prevention orientation and utilized Western medicine (Tang et al. 1999).

African Americans. Cultural factors that diminish the likelihood of screening among black women include fear, distrust, fatalism, and historic factors (Guidry, Mathews-Juarez and Copeland 2003). Focus groups with African American cancer patients in Philadelphia revealed negative reactions to being treated impersonally (Davey et al. 2010). Black women in Atlanta CHCs felt that cancer screening only heralded a disease that would kill them (Gregg and Curry 1994). Kaiser et al. (2011) found a lower level of trust in their physicians among black as well as English-speaking Hispanic women.

Implications

Disparities in health and health care are common, but they vary across groups and subgroups, and by location. They are interconnected, but in patterns that are not always predictable, with income, education, and age sometimes explaining disparities related to ethnicity and race and sometimes compounding them. Many elements of culture have been identified as possibly relevant, particularly among Hispanics, with mistrust of providers, a sense of fatalism, lack of knowledge and lack of self-efficacy often mentioned. Cultural influences also may extend to the influence of partners and neighborhoods on health care behavior. Limited English proficiency is the most consistent factor in health care disparities, with the remedies clearly established but the implementation of translation programs or use of bilingual providers often lacking.

Reducing Disparities

Efforts to reduce health disparities have led to new policies and new programs. At the national level, passage of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) Act in 1990 led to a new program for uninsured and under-insured women in all fifty states as well as all territories and tribal areas within the United states (CDC 1997) and lessened state-level variation in Medicaid coverage of screening (Boss and Guckes 1992). Subsequent passage and implementation of the federal treatment act (BCCPTA) in 2000 increased access to follow-up treatment among women identified in the screening program (NBCCEDP) as having cancer (French et al. 2004). A variety of other programs have attempted to reduce disparities among specific groups (Stromberg et al. 1998). Some efforts have focused specifically on improving communication through the use of translators.

These major policy changes and program developments have been followed by a period of dramatic increases in screening mammography. In the past decade, the screening rate has increased in the U.S. in every demographic group; disparities have also decreased among medically underserved populations (Peek and Han 2004). From 1992 to 2000, the percentage of women 50-69 who have never had a mammogram declined in the U.S. from 22.1% to 7.7% and racial and ethnic differences lessened, although disparities related to socioeconomic status and access to medical care remain (Peek and Han 2004; Schootman et al. 2003).

Research on various programs in multiple locations also indicates that disparities in access can be reduced. Women who use Community Health Centers (CHCs) are mostly up to date on cancer screening, compared to comparison groups, and meet or exceed the Healthy People 2000 objectives (Regan, Lefkowitz and Gaston 1999). An outreach program using nurse clinicians and public health workers increased screening program awareness, knowledge about breast and cervical cancer, and followup among African American women in Chicago (Ansell et al. 1994). Use of lay health advisers supplemented by nurse practitioners improved screening in another program (Margolis et al. 1998), and indigenous lay health workers seemed to improve screening behavior among Vietnamese women (Bird et al. 1998). An educational program that improved knowledge about breast cancer in turn improved the rate of breast cancer screening (Young, Waller and Smitherman 2002).

Providing translators for LEP patients has had good results. Clemans-Cope and Genevieve (2007) found that having translation services increases the use of appropriate health care services in low English proficiency patients, as well as adherence to treatment and health outcomes. The health behaviors of LEP patients who are able to use trained interpreters are similar to patients with high English proficiency (Ku and Flores, 2005).

Hispanics with legal documentation near the Mexican border prefer to go to a Mexican health care provider, mainly because the service provided is in Spanish and they are less costly (Fernandez and Morales, 2007). In response to previous research indicating that women in the Hispanic farmworker population with the greatest health needs were unable to read medical information, Meade et al. (2002) showed that using community members as educators could lead to high levels of cancer prevention behavior and great interest in educational classes. Program outreach delivered by bilingual case managers in New York City's NBCCEDP program eliminated the negative effect of low levels of health literacy among Spanish-speaking women on screening behavior (Garbers et al. 2010).

These positive program effects have not appeared in all groups studied and have been explained in some research by covariates. Inadequate insurance coverage reduced the effect of a culturally appropriate educational intervention on cancer screening (Sung, Alema-Mensah and Blumenthal 2002). The increased screening that followed use of case manager-navigators for African American women in Boston's REACH 2010 program was statistically explained by covariates (Clark et al. 2009). Managed care insurance nationwide has been associated with more reported screening among Hispanic and white women, but not among blacks or Asian/Pacific Islanders (Haas et al. 2002). Creating more "informed choice" about treatment by providing more information does not change decisions if personal or organizational barriers remain (Jepson et al. 2007).

Efforts to improve patient orientations by enhancing communication have also not always or entirely had beneficial results. A multi-national review concluded that better communication and information was one of eight factors that improved patient satisfaction with nursing care (Johansson et al. 2002) and a program to increase communication about cancer care among patients in Australia was favorably received (Jones et al. 2011). However, adoption of a widely used communication skills training program did not improve satisfaction among patients in a Portland, Oregon HMO (Brown et al. 1999) and a communication skills training program at 34 cancer centers in the UK did not have a statistically significant effect on patient satisfaction (shilling et al. 2003). In a recent study, Tan et al. (2011) found that patients who discussed cancer information more with their physicians at the time of diagnosis were actually more likely to report cancer-related issues at follow-up—apparently because the improved information had increased the salience of problems in the cancer survivors' minds.

These various program evaluation results indicate the potential for changing prevention behaviors and the need for effective translation services, as well as the challenges faced by those who seek to design effective programs and to statistically identify program effects. Two policy initiatives have stimulated many new programs and subsequent research and so require special attention: patient navigation and care coordination. Case management is often part of care coordination programs and is integrated with patient navigation and care coordination in the Massachusetts Care Coordination program, so it too will receive focused attention.

Patient Navigation

Patient navigation programs build on experiences with more limited programs that provide translation, education, and lay health advisor services, but they have a broader focus.

Harold Freeman, MD implemented the first patient navigation program at New York City's Harlem Hospital Center in 1990. Patient navigators at this hospital and two other sites were community members who were to reduce breast cancer care disparities through three processes (Vargas et al. 2008):

1) Removal of barriers to patient progress through the steps of care;
2) Documentation of patient barriers and flow;
3) Implementation of system-level change based on feedback about barriers. (p. 429)

In these early programs, patient navigators focused only on barriers to the plan of care; patient problems not directly related to the completion of care plans were not addressed (Vargas et al. 2008:428).

Since these early programs, the need for patient navigation assistance has increased as the health care system has become more complex in terms of technology, scientific knowledge, medical specialties and payment systems (Hopkins and Mumber 2007). Recognizing this need, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (S. 898 & H.R. 1812) authorized funds to reduce health care disparities with model programs “to recruit, train, and employ patient navigators who have direct knowledge of the communities they serve to facilitate the care of individuals.”

Definition

In spite of widespread experimentation with patient navigation programs, a general consensus has emerged about its definition: Patient navigation is a patient-centered process intended to reduce barriers to health care access and to improve engagement in the health care system. A more specific definition has been used in cancer care, the focus of most patient navigation programs:

> Support and guidance offered to vulnerable persons with abnormal cancer screening or a cancer diagnosis, with the goal of overcoming barriers to timely, quality care. (Freund et al. 2008)

Thus, patient navigation is most distinctive in its focus on “a defined set of health services that are required to complete an episode of cancer-related care,” with a focus on identifying barriers to receipt of care, facilitating timely access to care, and ensuring completion of care (Wells et al. 2008:2001).

Patient navigation is most often intended to reduce disparities in care delivery and, ultimately health outcomes with individuals and groups that have been underserved for reasons of culture, language, education, income, or location. Patient navigation services can be provided at all stages of health care, including prevention, screening, treatment and survival (Dohan and Schrag 2005).

Functions

Patient navigation programs after the original Harlem program have expanded the scope of services. Five somewhat overlapping functions appear to varying degrees in many patient navigation programs: assessment, relationship-building, instrumental assistance, health system connection, and community engagement. (The 2005 Act [S. 898 & H.R. 1812] mandating funds for patient navigation stipulated six functions, but one, providing information about clinical trials, is subsumed here as a “health system connection” function.) Each function is intended to reduce barriers to health care delivery when it is implemented successfully. No one function is unique to patient navigation; rather, it is when the services related to each function are used to reduce barriers to care experienced by specific clients that these functions can be termed patient navigation functions (Dohan and Schrag 2005:850).

Assessment: An initial assessment is the starting point of the patient navigation process, since it is intended to identify the barriers that must be overcome to maintain patient involvement in the health care system while health needs are met. Initial assessment can include measurement of depression and anxiety levels, a review of health education, approaches to problem solving, level of support for self-management, and help with goal setting. Assessment must then be ongoing to ensure that services continue until needs are resolved and that new services are offered as additional needs are identified. In some systems, patient navigators identify potential barriers using interactive phone assessments; some assign a level of service intensity based on a structured adherence risk algorithm (Battaglia et al. 2007; Ell et al. 2007; Ell et al. 2009; Fang et al. 2007).

Relationship-building: Developing an emotionally and socially supportive relationship with the patient is necessary in order to ensure that other services can be delivered, so it too is part of the essential foundation for the success of the patient navigation process (Ferrante, Chen & Kim 2008; Jean-Pierre et al. 2010).

Instrumental assistance: Providing instrumental assistance is the core of the patient navigation process. Members of disadvantaged populations are likely to experience problems with transportation, child care, insurance needs and symptom management, so helping patients overcome these problems is an essential part of the navigation process. Patient navigators may help patients with applications for financial assistance and connect patients with support systems and other resources (Ferrante, Chen & Kim 2008).

Health system connection: Patient navigators improve connections to the health care system and coordinate different elements of care so as to improve care continuity (Ell et al. 2007; HR 2651). They check about appointments, educate patients and their families about health care issues, encourage patients to state their needs clearly, and help patients and providers interact and communicate (Ferrante, Chen & Kim 2008; Nash et al. 2006). They may use psychological counseling (Ell et al. 2007), small group education sessions, or culturally and linguistically appropriate videos (Fang et al. 2007). Patient navigators may also link patients to clinical trials, when appropriate (Steinberg et al. 2006).

Community engagement: Community engagement extends the work of patient navigation to include outreach and education for potential patients and those who might refer patients, as well as networking with local health resources and conducting surveys about community care needs (Chyongchiou et al. 2008; Petereit et al. 2008). Although this function is not inherently part of the patient navigator role, it can be a natural addition to that role due to patient navigators' involvement in community settings and their familiarity with patients' backgrounds.

Patient navigators' primary focus on all or most of these functions creates a unique role focused specifically on barrier reduction (Gilbert et al. 2010). Patient navigators' focus is likely to be disease-specific and to include a concern with building and maintaining relationships with patients and empowering patients and their families (Fillion et al. 2009). Navigators are expected to respond flexibly to needs for instrumental assistance and health care connection, helping to overcome specific barriers as they are identified rather than delivering a fixed package of services (Dohan and Schrag 2005).

Organization

Health care systems organize their patient navigation programs in many different ways. Most often, patient navigation services are delivered by health care staff designated as patient navigators and who share some of their patients' social background characteristics, such as community of residence, primary language, or cultural background (Vargas et al. 2008:428). Patient navigation functions are often performed by single individuals designated as patient navigators, but some health care systems have used instead a team approach: in Illinois, teams comprised of a nurse, a social worker, and a lay navigator; in Rochester New York, two-person teams with a nurse navigator and a community navigator (Robinson-White et al. 2010).

Patient navigators are not the only health care system employees who can or do perform navigation functions (Dohan and Schrag 2005:851), so some patient navigation functions may be performed by others. Case managers also assess patients and help them to connect to the health care system (Wells et al. 1008:2005), while other community health workers may be responsible for community engagement activities (Fillion et al. 2009). The Massachusetts legislation authorizing patient navigation required that such services either include case management and psychosocial assessment and care or offer information and referrals to such services (House of Representatives 2005, Bill 2651).

Patient navigators are most often lay personnel who are not required to have advanced education, with little to no formal training in navigation services (Wells et al. 2008:2005). Where they have been specified, formal education requirements have ranged from a high school education with some health care experience (Rochester, NY) to any college degree (Newark, NJ) or a degree in social work or nursing (Texas). Some systems have sought cancer survivors as navigators (Santa Cruz, CA; Washington DC) and others have attempted to match the race of navigators to that of their patients (Robinson-White et al. 2010), although the value of using cancer survivors or matching in terms of race has not been tested.

Patient navigation programs also vary in their disease focus. Most programs have had a primary or exclusive focus on early stage cancer, with screening and follow-up testing for breast cancer being the most common (Wells et al. 2008:2005-2006).

Outcomes

The first patient navigation programs appeared to reduce average stage at diagnosis among cancer patients. Freeman, Muth and Kerner (1995) found that 87.5% of navigated patients in Harlem who had received an abnormal screening result completed recommended breast biopsies, compared to 56.6% of non-navigated patients. The five-year survival rate for breast cancer patients rose from 39% to 70%.

More recent research also identifies positive effects of patient navigation programs. Frelix et al. (1999) reported that the cancer detection rate at a clinic in the Bronx for socioeconomically disadvantaged women providing patient navigation was more than double

(12.9 per 1000 women screened) the rate for women throughout New York State (6 per 1,000 women). Psooy et al. (2004) found that a Nova Scotia patient navigation intervention decreased delays in the definitive diagnosis of detected breast abnormalities from 20 to 14 days. Battaglia et al. (2007) identified an increase from 64% to 78% in timely follow-up (within 120 days) for inner-city women with breast abnormalities after implementation of a patient navigation program. A more limited intervention using lay advisors to encourage women overdue for screening to complete a mammogram or Pap smear resulted in a ten percentage point increase in screening (Margolis et al. 1998).

Two composite reviews of the available research concluded that patient navigation improves health-related outcomes (Robinson-White et al. 2010; Wells et al. 2008). Including the most recently published research, 23 of the 27 studies that have investigated the effects of patient navigation on health-related outcomes, among patients at risk of or diagnosed with breast, cervical, prostate, colorectal or some other type of cancer, have identified positive effects of patient navigation on such objective health outcomes as screening rates, treatment adherence, or time to follow-up after problematic test results; two identified no effects and two reported mixed effects. Only seven studies used a randomized design, but all except one of these more rigorous tests identified improved outcomes among the navigated group compared to the non-navigated group. Ell et al. (2009) suggest that the null result of their randomized trial of patient navigation may have been due to high rates of referral of all poor women from the study site for freely available treatment.

Four of the 27 patient navigation outcome studies included measures of subjective outcomes, including patient satisfaction or another indicator of feelings about health care, while two studies focused exclusively on these subjective outcomes. All six of these studies reported positive effects of patient navigation on the subjective measures.

Carroll et al.’s (2010) qualitative investigation of patient experiences with a navigation program indicates the importance of subjective reactions. Nineteen of 35 respondents who were included in the qualitative analysis had been randomized to a navigation intervention and most anticipated that the instrumental assistance navigators can provide would be most important. However, after the navigation experience, almost all participants mentioned emotional support as most important. Navigated patients also mentioned the importance of having the navigator “being there” throughout the cancer care process, whether for emotional support or just as someone to protect against feeling isolated or disconnected from the health care system. Knowing that the navigator was an “insider” in the health care system also was valued by many navigated patients. Negative experiences with navigation focused on difficulties in relating to the navigator, but these were usually overcome. By contrast, negative experiences of non-navigated patients tended to continue through their care experience.

Some research has also focused on the role of patient navigators in reducing specific barriers. The barrier most frequently reported by cancer patients at an inner-city hospital in Pittsburgh and which took most patient navigator time was insurance and other affordability issues; this was much less of a problem at two hospitals in other locations. Other common barriers in the inner city hospital were transportation and fear about cancer. Needs for dependent care and assistance with activities of daily living were mentioned only infrequently. In total, the patient navigators spent an average of 2.5 hours per patient (Chyongchiou et al. 2008).

The National Cancer Institute’s current Patient Navigation Research Program (Freund et al. 2008) may soon add more precision to understanding of the effects of patient navigation.

Outcomes measured in the PNRP include timeliness of diagnosis, timeliness of cancer treatment, quality of life and patient satisfaction, and cost-effectiveness, as well as secondary outcomes like completion of therapy, quality of care, and the process of patient navigation.

Implications

Research on patient navigation should begin by identifying the functions of patient navigation in the system being investigated, as different activities reflecting these functions may have different results. The roles of other health care staff must also be considered, as must both objective and subjective outcomes, including emotional support patients receive from patient navigators. The ability of patient navigators to overcome barriers to health care must take into account the specific barriers in the particular setting being investigated.

Case Management

Case management and the work of case managers have evolved over time. The primary motivation for developing case management programs has been as a response to the challenges created by care fragmentation reimbursement changes, rising costs and pressures to reduce hospital stays, and increasing demands to improve care quality and continuity (Alves Casarin et al., 2003). By the 1990s, health care professionals generally agreed that case management should be used to coordinate community-based services, primarily for high risk clients likely to incur high costs (Casarin et al., 2002). Others have argued that health care systems should use case management regardless of their degree of service coordination and integration (Anthony et al. (2000).

Definition

Case management is a collaborative process of assessing clients' health care needs and then planning, implementing, facilitating, advocating, coordinating, and monitoring services required to meet those needs, as well as evaluating the outcomes of these services (Case Management Society of America, 2002; Hall, Carswell, Walsh, Huber, & Jampoler, 2002; Powell & Ignatavicius, 2001; Reimanis, Cohen, & Redman, 2001; Tahan, 1999; Tahan, Huber, & Downey, 2006a; Wetta-Hall, Berry, Ablah, Gillispie, & Stepp-Cornelius, 2004; Zander, 2002).

Case management's primary purpose is to coordinate the care that clients need as they progress through inpatient, outpatient, and community-based health care systems, with the goal of high-quality, cost-effective client outcomes and satisfaction (Case Management Leadership Coalition, 2003; Case Management Society of America, 2002; Hall et al., 2002). The Case Management Society of America (2002) urges that case managers engage with their clients in a mutual process of goal setting and identification of the means to attain goals, in order to ensure achievement of both client- and system-centered goals (and see Wetta-Hall et al., 2004). Such mutuality is also intended to avoid objectification of the service process, avoiding giving clients the impression that they are regarded as "cases" to be "managed" (Malcus and Kline, 2001).

Functions

The specific work activities of case managers can be categorized within eight domains—client identification and outreach, assessment, planning, implementation, coordination, monitoring, evaluation, and general activities (Anthony, et al., 2000; Forbes, 1999; Hall et al., 2002; Jennings-Sanders & Anderson, 2003; Maliski, Clerkin, & Litwin, 2004; Reimanis et al., 2001; Tahan et al., 2006a; Wetta-Hall et al., 2004; Zander, 2002). Although some (Tahan et al., 2006b) have developed more refined distinctions based on empirical analysis of case managers' reports of their work—such as distinguishing utilization management activities, psychosocial and economic assistance, and vocational rehabilitation as implementation functions—it does not appear that these finer distinctions extend the list of basic case management functions (Fawcett et al. 2007).

Client identification and outreach begins when a client seeks care for some health condition that requires coordination of various providers or services and the client and case manager connect. Case manager activities within the domain of *assessment* encompass identification of clients' financial situation, social needs, physical and mental health, living conditions, and family interactions. Activities within the domain of *planning* involve case manager-client mutual goal setting and prioritization of those goals, along with identifying needed health care and social services and practical assistance.

Activities within the domain of *implementation* focus on communication of the planned services to relevant stakeholders, client advocacy, facilitating linkages between clients and community resources, and actively assisting clients to progress through the health care system and obtain needed services. Additional implementation domain activities include teaching and supporting clients and tracking clients' receipt of services, assisting clients with their usual daily living activities and their management of coexisting medical conditions, assisting with changes in clients' behavior changes, maintaining care continuity, and bridging gaps in health care services.

Activities within the *coordination* domain emphasize coordination of service delivery and establishing relationships with referral services personnel. Activities within the *monitoring* domain focus on consultation with the health care team and monitoring of client progress.

Activities within the *evaluation* domain include examining case management processes, including the number of contacts and types of services, along with examining process and client outcomes, including goal attainment and indices of client health. Activities within the domain of *general activities* focus on advocating for service improvements, maintenance of confidentiality of patient data, and adherence to the standards of case management.

Several studies have described the frequency of performance of activities within these functional areas. Reviewing 18 studies of case management, Tahan (1999) found that coordination was most frequently performed (84%); assessment was second most frequent (53%), followed closely by planning (47%) and monitoring (42%) activities. Other less frequently performed activities included implementation (37%), evaluation (21%), advocacy and referrals (16% each), and case finding and reassessment (6% each).

Issel, Anderson, and Kane's (2003) survey of 66 prenatal case management programs in one state revealed that assessment occupied the largest amount of case manager time (24%), followed by education (20%), referral and service coordination (17%), monitoring client status activities (14%), and provision of emotional support (11%). Tahan and Huber (2006) found that at least two-thirds of 508 case manager job descriptions written between 2000 and 2002 included the following job activities and role responsibilities: communicates with health care team (89.6%), communicates with clients (88%), collaborates in care plan development (81.5%), identifies gaps in care plan (81.5%), completes patient assessment (78.5%), communicates with payers (77.4%), and implements cost-management strategies (67.1%).

Fawcett and colleagues (2007) described the activities of 20 nurse case managers who worked at Massachusetts Women's Health Network (WHN) contracting organization sites for breast and cervical cancer and cardiovascular disease risk screening. They found that case managers spent more time performing client service activities—those that involved services performed with or for the client--than bureaucratic activities—those that involved interaction with other staff and documentation of services. Frequently performed client service activities were tracking test results, finding/connecting with clients, assessing client needs, and educating clients. The most frequently performed activity was documenting services; the least, discharging clients.

Organization

Bedell and colleagues (2000) identified three basic models of case management. *Full service models* are an attempt to provide all clinical and support services needed by clients. *Broker models* involve little direct service, instead focusing on connecting clients to services provided by others and ensuring service delivery. *Hybrid models* are a combination of full service and broker models. An advantage of the hybrid model is that it can draw on nursing experience and skills to combine the best features of full service and broker models (Zander, 2002).

Others have distinguished case management programs in terms of their level of centralization. Lantz and colleagues (2004) described service delivery arrangements specific to the NBCCEDP as *centralized* within state health departments; *decentralized* across various clinical settings; *regional* within state health department regions; *localized* in city public health departments or visiting nurse associations; or *multi-level*, whereby case managers are deployed throughout more than one organizational level. Within the Massachusetts Women's Health Network (WHN), case management service delivery was categorized as centralized or decentralized in a way that differed somewhat from Lantz et al.'s (2004) categories. WHN centralized contracting organizations were large hospitals or medical centers that provided all

WHN services on site or in one instance, at several sites that were all part of a larger organization. WHN decentralized contracting organizations ranged from local hospitals to visiting nurse associations and health centers that subcontracted delivery of most WHN services to other health care facilities or individual clinicians in the area (Suri, Kramer, Palombo, & Piltch, 2005).

Individual attributes of case managers and their clients are related to the way their work is organized and the functions they perform. Jennings-Sanders and colleagues (2005) reported that the frequency of contacts between a case manager and a client decreased during the 12 months of their study of 158 women with breast cancer. The frequency of contacts varied somewhat for specific practice activities during each phase of the nursing process. In the assessment phase, assessing functional and emotional status required more contacts than other assessment activities. During the planning phase, planning care with the client required the most contacts. In the implementation phase, teaching required the most contacts. And, in the evaluation phase, monitoring the client’s progress required the highest number of contacts.

Client characteristics related to the frequency of case manager contacts included client age, living arrangements, race, income, and education (Jennings-Sanders et al. 2005). Women younger than 75 years of age had more contact with a case manager for symptom management than their older counterparts with breast cancer. In contrast, women older than 75 years of age who lived alone had a greater number of contacts with a case manager for psychosocial assessment, emotional support, and teaching. African American women had a greater number of case manager contacts than White, non-Hispanic and Hispanic women. Women with annual household incomes of less than $15,000 and women with less than nine years of education also had a greater number of contacts than those with higher incomes or those with more education.

Other relevant organizational factors include client caseload size and required documentation of activities, as well as space, staff mix, availability of interpreters, and practice standards (Issel, 1997; Issel & Anderson, 2001; Issel et al., 2003). For example, Issel et al. (2003) found that case managers working in larger programs spent significantly less time providing emotional support and more time on education than those working in smaller programs.

Various barriers can also influence the frequency of case manager activities. Wetta-Hall et al. (2004) identified three major categories of barriers—health, social, and system. Health barriers include clients' comorbid health conditions, such as chronic illnesses and psychiatric disorders. Social barriers encompass clients' immigrant status, limited English proficiency, lack of permanent housing, cultural diversity, fear of bills and other economic issues, lack of transportation or child care, making time for appointments, and fear of health care systems. System barriers include difficulty case managers experience in maintaining contact with clients for follow-up care and health care providers' biases and lack of cultural sensitivity.

Fawcett et al. (2007) reported that client service activity frequency was correlated with client caseload size, social barriers, overall workload, satisfaction with the way activities are carried out in the WHN, special training in WHN policies and procedures, and contracting organization service delivery arrangements. Bureaucratic activity frequency was correlated with caseload size, workload, months as a WHN case manager, system barriers, satisfaction with the way activities were carried out in the WHN, and special training.

In contrast, Park et al. (2009) reported that case management practice activities did not vary with the organizational setting. They found that similar activities were performed in hospitals, rehabilitation facilities, health insurance companies, managed care organizations, case management companies, workers’ compensation agencies, and third-party administrators.

Outcomes

Older women with breast cancer who received case management services reported that their case managers helped with management of coexisting medical problems, provided support and education, assisted with activities of daily living, and helped them navigate the health care system (Jennings-Saunders & Anderson, 2003). Heinemann and colleagues (2004) reported that case management was associated with enhanced client life satisfaction and family satisfaction among clients who had suffered a traumatic brain injury and experienced substance abuse. Goering, Farkas, and Wasylenki (1998) found that clients with severe psychiatric disabilities who were in an innovative case management program and who showed improved instrumental role functioning at 6 months after hospital discharge had better housing conditions, fewer symptoms, and better social functioning than those who did not improve. Research has also suggested that the cost of care can be reduced by case management (Heinemann et al., 2004).

Schutt et al. (2008) documented high levels of satisfaction with case management services in the Massachusetts NBCCEDP, the Women’s Health Network, but also found that client satisfaction varied with client ethnicity and language. Hispanics who preferred to speak Spanish or Portuguese—presumably those less acculturated—were more satisfied with case management services than were native English speakers, while those who preferred to speak English—presumably those who had been in the United States for a longer period—were less satisfied with case management services than were native English speakers. These findings suggest that patients’ point of comparison may be a key influence on their subjective feelings about case management services they receive.

Implications

Evaluation of case managers’ impact on health outcomes must begin with identification of their functions in the health care system, including their role in care coordination and taking into account the stage of the care process for which they are responsible. Evaluation must also take into account the characteristics and health needs of case managers’ patients.

Care Coordination

Care coordination is an important property of health care systems as well as a key aspect of patients' experience of health care. When care delivery is not coordinated across segments of a health care system, resource use will not be maximized and health care outcomes will not be optimized. When patients do not experience their care as coordinated, they are less likely to obtain all elements of the care they need and to adhere to treatment directives. Most patient navigation and case management programs have care coordination as one objective, but evaluation of care coordination in health care requires a broader focus.

Definition

In general, coordinated care in healthcare is "the delivery of systematic, responsive and supportive care to people with complex chronic care needs" (Ehrlich et al. 2009). More specifically, care coordination is often used to refer to multidisciplinary teams involving two or more providers from different specialties providing care to a group of patients. However, the term has also been used in reference to "disease management" strategies--which have no consistent definition; to case management--which involves the assignment of one employee to coordinate care (with the characteristics and duties of those employees often poorly defined); to "care integration"; and to "interprofessional education"--in which diverse employees are trained together. These diverse strategies are used to coordinate care in a variety of settings and for a variety of health conditions, most often the chronic conditions of mental illness, heart failure, and diabetes. The focus can be on coordination at the client level, on teamwork among care providers, or on systems-level coordination and integration (Ehrlich et al., 2009).

The Agency for Healthcare Research and Quality (AHRQ) reviewed definitions of care coordination used in publications prior to 2007 and, from 41 different definitions, developed a working definition containing five elements found in most care coordination programs: multiple participants who are interdependent and who require adequate knowledge and exchange of information in order to coordinate activities and facilitate health care delivery:

> *Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.*
>
> (McDonald et al. 2007: 41).

Functions

Most of the 15 care coordination programs funded by a multisite demonstration of the Center for Medicaid and Medicare (CMS) (2000) provided patient education that used standardized curricula to deliver factual information intended to improve adherence to medication, diet, exercise, and self-care guidelines. The programs sent patients' doctors regular written reports on their patients and also consulted with pharmacies about medication issues, although they relied on the patients to provide a list of their medications. Only four programs attempted to increase doctors' adherence to evidence-based or guideline-based care, but most programs taught patients how to communicate more effectively with their doctors. Most programs also arranged support services such as transportation or home-delivered meals, either directly or through referrals, although these services were not often needed (Peikes et al. 2009).

McDonald et al. (2007:6-7) reviewed care coordination interventions for patients with congestive heart failure, diabetes mellitus, serious mental illness, stroke and depression. Among 43 programs, seven core tasks were identified as essential to the creation of coordinated care. These tasks and the organizational features that facilitate them are identified in a summary table (McDonald et al. 2007:6):

Table A. Components of care coordination

Component	**Comparable Domains Noted by Others**
ESSENTIAL CARE TASKS and *Associated Coordination Activity*	
ASSESS PATIENT *Determine Likely Coordination Challenges*	Initial Assessment (M)
DEVELOP CARE PLAN *Plan for Coordination Challenges and Organize Separate Care Plans*	Proactive Plan of Care and Follow-up (NQF) Problem Identification and Care Planning (M)
IDENTIFY PARTICIPANTS IN CARE AND SPECIFY ROLES *Specify Who Is Primarily Responsible For Coordination*	Healthcare 'home' – source of usual care selected by patient (NQF) Program Staffing (M) Provider Practice (M)
COMMUNICATE TO PATIENTS AND ALL OTHER PARTICIPANTS *Ensure Information Exchange Across Care Interfaces*	Communication-available to all team members, including patients and family (NQF) Communication (M)
EXECUTE CARE PLAN *Implement Coordination Interventions*	Service Arranging (M)
MONITOR AND ADJUST CARE *Monitor For And Address Coordination Failures*	Ongoing Monitoring (M)
EVALUATE HEALTH OUTCOMES *Identify Coordination Problems That Impact Outcomes*	Quality Management/ Outcomes Measurement (M)

COMMON FEATURES OF INTERVENTIONS TO SUPPORT COORDINATION ACTIVITIES *and Examples*

INFORMATION SYSTEMS *Electronic medical record; Personal health record; Continuity of care record, Decision support* ; *Used for population identification for intervention*	Information systems - the use of standardized, integrated electronic information (NQF) Information Technology and Electronic Records (M)
TOOLS *Standard protocols, Evidence-based guidelines, Self-management program, Clinician education on coordination skills, Routine reporting/feedback*	Patient Education (M)
TECHNIQUES TO MITIGATE INTERFACE ISSUES *Multidisciplinary teams for specialty and primary care interface; Case manager or patient navigators to network and connect between medical and social services; Collaborative practice model to connect different setting or levels of care; Medical home model to support information exchange at interfaces*	Transitions/Handoffs - transitions between settings of care (NQF)
SYSTEM RE-DESIGN *Paying clinicians for time spent coordinating care; Changes that reduce access barriers including system fragmentation, patient financial barriers - lack of insurance, underinsurance, physical barriers - distance from treatment facilities*	Environmental Level (e.g., consideration of alignment of incentives); Health care system reorganization (IOM)

NQF = National Quality Forum domain; M = Mathematica evaluation area; IOM = Factor noted in report on “Priority Areas for National Action”

Organization

The operations of the 15 care coordination demonstration programs funded by the Centers for Medicare and Medicaid Services (CMS) in 2000 were each investigated for at least one year. The fifteen programs were not required to adhere to a particular program model, but subsequent research identified some characteristics in common across the programs—although also many differences. All but one of the programs used registered nurses as care coordinators who assessed patient needs and developed a patient care plan. Caseloads for the care coordinators ranged from 40 to 70 patients per month, with an average of 1 to 2.5 contacts per month and a high of 4-8 contacts per month. All the programs relied primarily on phone contact with patients, although four required at least one in-person visit each month. Services in seven programs were guided by an explicit behavioral change model (such as Prochaska's transtheoretical model) and several programs provided special help at the time of patients' transition from the hospital (Peikes et al. 2009).

Outcomes

Several specific studies have identified effects of care coordination on particular outcomes. Mangrum (2006) found that coordinating substance abuse and psychiatric care reduced psychiatric hospitalizations, both Kilburne () and Druss et al. (2006) found a positive effect of coordinated care for medical and psychiatric problems on physical health, Vickrey () reported improved quality of life among dementia patients receiving guidelines-based case management, and both Jen Associates () and Cohen () reported that broad assessment and service coordination reduced nursing home entry. One exception was Brown et al.'s (2008) conclusion that care coordination programs involving patient education had no effects on patient behaviors, patient health or quality of care.

McDonald et al.'s (2007:105) composite review for the Agency for Healthcare Research and Quality (AHRQ) found sufficient evidence to conclude that care coordination in the form of multidisciplinary teams, case management and disease management programs is associated with improved outcomes for heart failure, stroke, diabetes, and mental illness. Evidence was very limited on cost effectiveness, but one review concluded that care coordination was cost effective for improving outcomes in patients with depression.

However, these generally positive conclusions are called into question by the findings that the 15 CMS-funded care coordination programs had little effect on health outcomes, in spite of their patients being more likely to report having received health-related education and help in arranging care. Only one program reduced annual hospitalizations by a significant degree, none reduced regular Medicare expenditures, none improved self-reported understanding of diet and exercise, self-reported diet, exercise, or medication adherence, and there were no clear improvements on outcomes-of-care measures (preventable instances of hospitalization). There were only a few improvements in the many self-reported measures of functioning (Peikes et al. 2009).

In an exception to these generally negative findings of the CMS evaluation, patients in two coordinated care programs reported more health education on several topics, more help in arranging care, and were more satisfied with specific aspects of their regular health care. Nonetheless, in one of these programs, patients did not improve in patient behaviors, quality of life, activities of daily living, or preventable hospitalizations, while in the other of these programs only several of these indicators registered a trend toward improvement. One other program reduced hospitalizations and expenditures, but these effects were entirely in the highest severity cases. Physicians generally liked the care coordination programs for their reports on patients and the instrumental help they provided to patients, and felt they decreased doctors' paperwork and phone calls and increased quality of care. However, the doctors did not think the programs had much effect on coordination with other physicians, continuity of care, duplicate testing, communication with family members, or patients' self-management behaviors (Peikes et al. 2009).

The two most effective CMS care coordination programs had several distinctive features: much more frequent in-person patient contact per month (one contact monthly, on average, compared to one-third), patients who tended to be at moderate risk of hospitalization (rather than at no risk or at very high risk), a much more concerted effort to teach patients how to take their medications, closer relations with local hospitals to manage patient transitions out of the hospital, and frequent opportunities for the coordinators to interact with physicians. The combination of ongoing care and special efforts related to transitions seemed particularly important (Peikes et al. 2009).

The discrepant results of the AHRQ review and the CMS review may be explained by several factors (McDonald et al. 2007). One such factor is the correspondence between the information processing requirements of a health care system and its capacity for handling those requirements. From the standpoint of organizational design principles, information processing requirements increase with the interdependence of actors in the setting, the degree of uncertainty in the situation, and the complexity of the situation and the patients. Requirements for more information and a bi-direectional information flow result in greater interdependence, an unpredictable course of disease or treatment leads to greater uncertainty, and patients with multiple chronic problems and from diverse settings require more information about symptoms, diagnoses and monitoring, thus producing greater complexity.

A healthcare system has more information processing capacity, and thus is more able to respond to greater information processing requirements, if it groups participants together, as in a multidisciplinary clinic, develops structural linkages involving a designated coordinator role or a coordinating committee, or uses operational processes that standardize, adjust, or monitor information or otherwise increase resources for coordination (see table, from McDonald 2007).

Since effective and efficient coordinated care is more likely if the information processing requirements of the system match its information processing capacity, poor fit in this sense could explain poorer care coordination results.

Table 17. Operational processes

Operational Process	Definition	Healthcare Examples
Standardization	Formalized mechanisms that pre-specify the roles, responsibilities, and activities; the specifications of intermediate outputs; and/or the skill sets needed to perform specific activities.[309, 310]	- Practice guidelines - Care maps – Protocols - Clinical pathways - Checklists - CME (continuing medical education) that aims to standardize skills or knowledge
Adjustment	Mechanisms that facilitate ongoing assessment and adjustment of roles, responsibilities, and decisions among multiple participants, either between individual participants or among a designated group of participants.[91, 130, 141, 305, 309, 310]	- Individual performance feedback - Team meetings - Consultations - Multidisciplinary patient rounds
Monitoring	Mechanisms to facilitate timely assembly of information regarding delivery of services and changing patient care needs [91]	- Planned visits - Group visits - Automated relay of clinical information from home-based monitoring devices
Organizational Supports	Resources that influence the ability of an organizations to implement coordinating mechanisms.[91, 310]	- Co-location of care sites - Information systems (e.g., computerized decision support systems) - Staffing decisions - Incentives

Certain organizational features that improve relationships may also be associated with better care coordination: frequency, timeliness, and problem-solving aspects of communication among participants in care; helpfulness; shared goals and knowledge; and mutual respect. Other potentially important organizational features are the predispositions of participants to coordinate, including attitudes of physicians and nurses toward care coordination, resources available for coordination, and the extent of pressure for coordination.

The relevance of these characteristics for care coordination and their importance for its success are indicated in other research on the operation of care coordination programs. Ehrlich et al. (2009) identified variability in partnerships, networking, collaboration, knowledge transfer, person-centered practice, and support for self-management. Galland (2006) highlighted the importance of perceived self-efficacy. Tringali et al. (2008) described the role of a clinical nurse specialist in coordinating care between onsite hospital clinics, hospital beds, community practice sites, and home care. Carroll et al. (2010) found that patients with a patient navigator received assistance with information needs, problem solving and logistical aspects of cancer care coordination. In a study of the effects of liver service provider characteristics, Hinami et al. (2010) concluded that care coordination improved with the extent of "ownership of patients," broader delegation of tasks and self-assignment of responsibilities (among hepatologists). Hansson et al. (2010) identified a history of local and personal informational cooperation and shared responsibilities as helpful factors in care coordination.

Results of research on the value of electronic medical records for care coordination have been mixed. Graetz et al. (2009) concluded that they improve coordination of information transfer and communication of treatment goals, but do not affect agreement on roles and responsibilities. O'Malley et al. (2010) concluded that electronic medical records do not focus on or improve care coordination, except for within-office coordination.

Multiple barriers to effective care coordination have been documented. Hawley et al. (2010) argued that good care coordination requires accurate patient understanding of treatment and care management options. In a survey of breast cancer patients in Los Angeles and Detroit, Hawley et al. (2010) found generally positive ratings of care coordination, but lower perceptions of care coordination and less satisfaction with care coordination among those with low health literacy. Race and ethnicity had no independent effect. In a study of multi-disciplinary teams in Australia, Walsh, Harrison et al. (2010) found confusion about the cancer care coordinator role, insufficient team meetings, inadequate communication with public and private sectors, and with family physicians, and inequality of health service access in rural areas and lower levels of supportive and psychological care in private systems, as well as a shortage of GPs. Hansson et al. (2010) also highlighted unclear roles and routines as unhelpful factors.

In qualitative interviews with 20 patients, four carers, and 29 health professionals, Walsh, Young et al. (2010) identified multiple barriers to cancer care coordination: recognizing health professional roles and responsibilities, implementing comprehensive multidisciplinary team meetings, transitioning of care, falling through the cracks, inadequate communication between specialist and primary care, inequitable access to health services, managing scarce resources. Walsh, Harrison et al. (2010) concluded that effective patient care coordination requires a key contact, initial needs assessment, ongoing communication and cooperation, sufficient access and navigation, adequate organization of patient care, sufficient and timely information to the patient, and service delivery.

Implications

It is important to identify the specific functions attempted in a care coordination system and how the system is organized to carry them out, taking into account each of the elements in the system. Measurement of system operations alone cannot identify their efficacy in coordinating care; the need for coordination the system confronts must also be measured and compared to those operations.

Satisfaction

Achieving high levels of patient satisfaction is an important goal for health care services and a key focus of quality assurance efforts (Aharony and Stasser 1993). Patient satisfaction may influence adherence to treatment recommendations, preventive screening schedules, and followup plans, and so also influence health outcomes themselves (Bakker et al. 1998; Borders, Warner, and Sutkin, 2003; Ware and Davies, 1983). Dissatisfied patients are more likely to change their health care provider and so diminish the continuity of their relationship with a provider (Marquis, Ross, and Ware, 1983; cf., Mirowsky and Ross, 1983).

Levels of Patient Satisfaction

Fortunately, given the importance of patient satisfaction, research in most health care settings has found high levels of patient satisfaction. Prostate cancer patients were very satisfied with telephone follow-up services provided by nurses (Anderson 2010), women were very satisfied with their experiences in various cancer screening programs (Bakker et al., 1998; Foxall, Barron, and Houfek, 2003),

Influences on Satisfaction

Patient ethnicity and related cultural orientations has been related to patient satisfaction in some (Ellmer and Olbrisch, 1983; Kaiser, et al., 2011), but not all research on health care (Hawley et al., 2010). Better communication between health care providers and patients and greater patient literacy has been associated in much research with more patient satisfaction (Bredart, Bouleuc, and Dolbeault 2005; Brody et al., 1989; Cleary, 1988; DiMatteo and Hays, 1980; Eisenthal, Koopman, and Lazare, 1983; Eyigor et al., 2009; Foxall, Barron, & Houfek, 2003; Hawley et al., 2010; Hawley et al., 2008; Jackson, Chamberlin, & Kroenke, 2001; Shilling, Jenkins, & Fallowfield, 2003; Williams & Calnan, 1991), and this could in turn help to explain lower levels of satisfaction in patients for whom English is a second language (but see Hawley et al. 2008). The findings of Schutt et al. (2008) suggest that differences in ability to communicate in English and in reference groups for evaluating health care may create inter-ethnic differences in satisfaction (see also Calnan, 1988; Kaiser et al., 2011; Jackson, Chamberlin, & Kroenke, 2001). This interpretation is consistent with Calnan’s (1988) earlier emphasis on the importance of taking into account goals, prior experiences, and health images when attempting to account for lay perceptions of the adequacy of health care. However, several studies have not found a communication-satisfaction linkage (Brown et al. 1999) and the impact on satisfaction of patient expectations and values seems to be relatively minor (Linder-Pelz, 1982).

The quality of provider-patient relations has also been identified in much research as an important influence on patient satisfaction (Cleary, 1988; DiMatteo and Hays, 1980; Johansson, Oleni, & Frielund, 2002; Williams & Calnan, 1991).

Other correlates of patient satisfaction identified in some prior research include age (Linn, 1975; Pope, 1978; Shilling et al., 2003), extent of depression (Linn, 1982) extent of fulfillment of patient requests in the clinical encounter (Like and Zyzanski, 1987), and involvement of partners in health care visits and decisions (Zeliadt et al., 2011). Satisfaction may also differ between health care agencies due to such organizational characteristics as level of bureaucratic rigidity, although it is not clear if such organizational effects extend to many dimensions of satisfaction (Greenley and Schoenherr, 1981).

Conclusions

Research on programs to lessen health care disparities must be informed by a model that takes into account multiple patient characteristics and their health needs, as well as one that recognizes the interrelations among different occupational roles in the health are system. Both patient navigation and care coordination programs have been adopted as part of efforts to reduce health care disparities, and ultimately disparities in illness, but they have most often focused on different patient populations. Patient navigation programs were initially focused on patients at risk of cancer and many remain so, while care coordination programs have primarily attempted to improve care for patients with chronic health conditions. As a result, the challenges that these two different programs confront in reducing health and health care disparities are fundamentally different. While reducing cancer risk requires an intense focus on timely testing and treatment, with a discrete end point, improving care for chronic illness requires a focus on life-style interventions and a long-term relationship.

A program that combines patient navigation and care coordination, as well as case management, has the potential to have a more robust impact on health care and, ultimately, patient health than a program that includes only one or the other element. However, there is as yet little evidence that patient navigation can improve outcomes for patients with chronic health problems, or that care coordination can improve the timely diagnosis and treatment of cancer among at-risk patients.

Measurement decisions in research on diverse populations may also affect the identification of behavioral disparities and estimates of changes (Ellmer and Olbrisch 1983). Different survey questions elicit different self-report rates of mammography screening for black and white women, although not for Hispanic and white women (Fiscella, Franks and Meldrum 2004). Comparison to medical charts indicates a considerably increased rate of self-reporting of mammograms and Pap smears by low income minority women, compared to their actual behavior (Paskett et al. 1996).

It is also important to use properly translated research instruments to assess health status, orientations and behaviors in LEP populations (Cella et al. 1998; Dias Ribeiro de Paula Lima, et al. 2005; Wang et al. 2010). Translations in Spanish must take into account variations between Hispanic subcultures in some cultural beliefs and in the use of particular words and phrases (Medina-Sheperd and Kleier 2010; Oetzel et al. 2007; and see Morales et al., 2000).

Methodology

Evaluation of the Care Coordination Program (CCP) focused on both the process by which the program is delivered and the impact of the program on patients. A comprehensive review of research on patient navigation and related issues concerning case management, care coordination, and service preferences helped to guide the research, and recognition of the complexities of program delivery across 17 service vendors led to use of a mixed methods research design.

A semi-structured interview protocol was used in interviews with almost all program patient navigators (32), case managers (25), and program coordinators. Interview questions focused on staff backgrounds, orientations, and work experience and the functions of patient navigators and case managers in service provision. Interviews also identified facilitators of and barriers to efficient and effective service delivery. All interviews were recorded and transcribed and the resulting textual data from patient navigators and case managers was with the assistance of qualitative analysis software (NVivo 9).

The evaluation of program impact focused on the experiences of patients with the Care Coordination Program and the factors that influenced their health and health care. Data were collected with a statewide phone survey of a representative sample and through in-person interviews with a small number of patients at different program delivery sites.

The original sample list of all people who received health care services contained 13,171 people. Upon a close examination of the data contained in this file, 2,413 people were eliminated from consideration for the study because there was no indication they had visited a program clinic site within the past 12 months. An additional 131 people were eliminated from consideration because they either had no address on the file or they had an address outside

Massachusetts, indicating they had moved outside the area serviced by the Coordinated Care Program. This left 10,627 people still eligible for selection into the study. Also upon closer examination of the data on the sample file, it became evident that a number of people did not have telephone numbers to be called. Furthermore, it was discovered that virtually all of these people without telephone numbers came from one of the 17 program sites. It was decided that eliminating this site from the study was not an option as it could potentially bias study results as it was a larger site. Therefore, the Center for Survey Research staff made every effort to find phone numbers for these people, through calling Directory Assistance and using public online resources, primarily the online white pages. Telephone numbers were located for approximately 56% of people drawn for the sample without telephone numbers (Roman, Bolcic-Jankovic, Mahmood 2012).

The final sample consisted of 383 persons (out of a target of 400). Nearly 90% of the people who could be located and were eligible completed the interview. From these results, the overall survey response rate can be computed as (0.5767) x (0.8970) = 0.5173 or 51.73%. If we consider all sample cases that could not be located as non-interviews, then this survey response rate becomes (0.3662) x (0.8970) = 0.3285 or 32.85% (Roman, Bolcic-Jankovic, Mahmood 2012).

The representativeness of the obtained sample can be established empirically by comparing location and demographic characteristics for the entire population of Care Coordination patients to those included in the final phone sample. There were only a few discrepancies between the distribution of patients across sites in the phone survey sample compared to the total patient population. The one site among the total of 17 that did not provide patient phone numbers for the phone survey (and for which CSR sought phone numbers through online and other directories) was underrepresented (7.8% of the phone sample compared to 16.4% of the population), while a large Boston site was overrepresented (19.6% compared to 9.3% of the population) and a health center in another city was underrepresented (4.7% compared to 9.8% of the population).

In terms of primary language, 87.7% of the patient population spoke English (41.1%), Spanish (32.0%), or Portuguese (14.6%), compared to 93.2% of the phone sample (English=47.5%, Spanish=35.2%, Portuguese=10.5%). The overrepresentation of these three languages in the phone sample reflects the fact that the survey instrument was only available in these three languages. Almost half (47.2%) of the phone survey sample was identified as of Hispanic origin in DPH patient records, compared to 44.4% of the entire patient population. DPH records identified 41.0% of the phone survey sample as white, compared to 48.2% of the patient population. Overall, these small differences in themselves indicate little potential bias in statistics based on the phone survey sample.

The phone survey instrument was translated into Spanish and Portuguese; patients who could not answer in English, Spanish, or Portuguese were not interviewed. Questions in the phone survey instrument were designed to identify relation to the health center and patient navigator, ethnic and linguistic background and some other sociodemographic characteristics, current health status, including levels of depression, use of health services, perceived barriers to the use of health services, and several measures of satisfaction with health services. .

Thirty patients were selected from the phone interview sample for more intensive interviews about program experience and orientations. There were no statistically significant sociodemographic or attitudinal differences between this subsample and the rest of the phone survey sample.

The intensive interview protocol included questions about health care experiences, the role of the patient navigator, satisfaction with the patient navigator and other health care providers, the problems experienced in getting health care and perceptions of care coordination. Interview questions also assessed social contacts and the importance of linguistic and ethnic identification.

Staff Interviews

Overview of Program Operations

The primary goal of the Care Coordination Program is to provide holistic care that can meet the needs of patients with chronic illnesses as well as those elevated cancer risk. A program case manager explained the importance of this goal.

> Sometimes you know patients can get very discouraged because they don't have the economic means or the education to get what they need, they don't know how to navigate through the system but I really think by proper assistance and you know teaching and education and treating people equally that they are much better off.

Achieving this goal required changes in both the operation of the health care system and in the orientation of the patients served by that system.

The process was not yet completed, according to one case manager.

> Often times the request…it could be behavioral health, it may be somebody saying, 'this person needs case management' and what I've worked really hard at over the last couple years is to get people to say, 'what do you mean?' or you know, I won't accept that kind of a request it's like exactly what is your

> expectation? What is your understanding of the problem and what is it you're hopeful that I can help the patient with? That's you know, 'cause that's been a challenge because when I came here case management was very vague. It meant if somebody doesn't know what to do they come to the case manager and in many ways it's still that way because the culture here has not been as conducive as it might be to set those structures up. I periodically write up my thoughts about how a case management team might function, how they could do that, what they would have to do in the budget but that falls on somewhat deaf ears. There are so many other things going on. That's a fair description.

Program directors at many sites described the key operational changes induced by the Care Coordination Program as being a shift to a team approach and a focus on the whole patient. The Program Director for a large multi-site health center reported that the Care Coordination Program had led them to develop a collaborative team approach and to break down communication barriers between disciplines. They had learned from the DPH program to care for the whole patient, rather than following "a factory" model with a focus on only the most immediate health problem, and then had adopted this approach for all of their patients. The Program Director for another large health center said that the Care Coordination Program led to a shift from just training individuals to training staff to work as teams, with cross-training so that team members were familiar with their teammates' work as well as with their own. The Program had also increased communication with specialists about patient needs and at one center had prompted regular meetings of a chronic disease group.

A patient navigator described the team approach at her center:

> We also work with the teams here at the clinics, so I will also do a lot of delegating so I will delegate some tasks to the medical assistants and front desk staff for patients who need follow-ups, so I'll work with them and just, you know, call patients and get those appointments scheduled, I even have some patients walking into the clinic, asking to speak with me, so I will meet with the patients and, I do a lot of work around, I mean you get all these… not only the outreach calls but you know patients will come to me if they have issues with certain things like "my medications weren't covered at the pharmacy what should I do? I lost my insurance where do I go? I can't come in for my appointment." So it's kind of…I have to work with these barriers and if I don't have the solution I kind of have to, direct the patient to the right appropriate person, so it's a really collaborative approach with the different team members and helping the patient with that issue.

Care Coordination's focus on caring for the whole patient also led some health centers to realize the importance of patient navigators and educators for patients with their "very, very complex health needs." Patient navigators and case managers were described as facilitating long-term relations with patients and allowing better follow-up with patients who received abnormal test results. The program's emphasis on patient education about healthy lifestyles and regular reminders about due dates for prevention screening were seen as very helpful. One Program Director spoke of the patient navigators as facilitating engagement with patients in the community by dealing with “the social aspect” of patient care. The Program also encouraged centers to emphasize hiring linguistically and culturally competent staff who could relate to the whole patient and understand their community context. One Program Director described the Program’s Risk Reduction Educators as “phenomenal,” both spending time to talk with patients about their quality of life and connecting in the community through health fairs and collaborating with community organizations.

A patient navigator described her holistic approach to patient care for a very complex case.

> I help them with the medical records, I help them also explaining how to fill out the medical history, also the patient information form. …I help to fill out the questionnaire for the DPH, so there are the areas that I help. With the literacy I don’t directly help them to understand the new patient orientation, what is the clinic what are the rules who are the providers, how the clinic functions what is urgent care doctor, what is the…where they can park their car, what is the transportation that they can catch to come here, what are the buses available. I explain about the free services in the clinic: risk reduction education, family planning, social services. I locate them inside of the building …. All the services that we have, nutritionist, diabetic educator…doctor, the psych visits, the mental health services, although very limited in this clinic but I explained

them what it is …. Housing once in a while I get a patient that has housing problems, then I send them to N if she can help or I check, I Google the housing and now I have like paper with the list where I can send them when they start the outreach. Food stamps, like some churches some community services that can help that is around. Employment issues I helped one patient once that he was like, he was from Colombia, he was handicapped, …he was in a wheel chair, he was shot and he received a shot in the vertebrae and he … came here because the FARC was threatening him, so he came…he had a lot of problems he could not, he was living at the third floor of the house, he had to get the help from a friend that he didn't know so well and to take him from the third floor, put him in his back – in the friend's back, because he had no elevator in the building for he comes to the clinic and he didn't have this what they call this wheel chair that is like a mobile the one that you can shoot off like…so I helped him check in the place whether the pharmacy he could get it and a place that he could get in Cambridge and then another shelter because he's at this place, the guys were using a lot of drugs and was like not clean at all, everybody was very dirty there, like the place by itself so he had a lot of issues a lot of need and then he came many times he need insurance, he needed transportation, issues he had tons of things, so it's a type of patient that I…it's the one I would say of all of

> them that I felt grateful to be in a position to help someone, to really offer service.

A case manager described the impact of Care Coordination on their center's health care delivery approach.

> just looking at the, the health center before and after Care Coordination. I, you know, if a person comes in now, there's a specific, specifically designated person that's gonna talk to them about their preventative health needs. Have you had a physical? Do you understand what a Pap smear is? Do you know what, what a mammogram is and where you had your last one? Have you ever heard of colon cancer or colonoscopy? We have educators that can talk to you about it. I mean, it's, it's a world of difference to have people come in, it's got, you know, we've created, with our IT, we've created a whole template to help us to track and, see when patients are due for, for care. Also, they support people going to the nutritionist and encouraging nutritionist appointments. So, there's, there's a whole, it's like a whole different orientation and then a lot more support for people, to encourage them to do preventative screenings and, we have also, group, group ed visits and the chronic disease self-management groups that people can come to to sort of cope with and—to learn how to cope with and take care of themselves when they have a chronic disease. Diabetes, asthma, hard disease. So, there's a lot of resources there

> for patients and it's kind of a, just a different worldview on how to, how to care for, how to care for patients.

In spite of these examples of successes, frustrations with patient orientations were common and some had had initial difficulties enrolling patients in the Care Coordination Program. The patients' focus was often on resolving their immediate health needs, rather than on seeking all the care they needed. Patients too often didn't show up for follow-up appointments due to work demands or family obligations. Language barriers and illiteracy were often cited as contributing factors in inadequate follow-up, although the program was seen as very helpful in overcoming language barriers. Several program directors commented on the value of the program's patient navigators and/or risk reduction educators in identifying patient-specific barriers to health service delivery and in changing patient orientations.

It seemed to some program directors that operations could be improved by providing patient navigators and risk reduction educators with more regular education about issues in relevant medical areas. Staff turnover also made ongoing training about the program important. Some directors emphasized the importance of improving staff knowledge of and connections to other community programs. One reported some tension between the dual responsibilities of their patient navigators, performing work for the clinic and delivering services for the DPH program.

Several program directors reported difficulties in integrating the Care Coordination Program in their existing health care operations and making other personnel aware of it. Most felt this process had succeeded—"it's really going well, fantastic"—although one director acknowledged that associated clinics did not report much benefit from the program. Some providers in rural areas found that it was still difficult to get health centers to refer patients to the Care Coordination Program and that the program was only a minor part of these clinics' operations. Ultimately, some program directors said that all patients should have a patient navigator and urged that patient navigators and care coordination be integrated in their clinics' regular operations, rather than maintained as a separate program.

Program implementation had not always been easy.

> I think it probably took a good two years before people understood what our responsibilities were and how we were to be utilized for patient care; how do we coordinate the care? How do we bring it together? And it was a learning curve for us as well as for the providers in the health center but when you do something like that and you have this small group of people that's trying to implement a program that's intended to umm grow and it's intended to affect the number of people that you have in a practice it really takes a long time to get people on board because there are certain responsibilities that need to take place in order for it to happen and sometimes it didn't happen as easily as we wanted it to.

A case manager at one large health center just didn't feel the program had yet been integrated well in ongoing operations.

> I don't think that the program is well integrated, I don't think is well utilized by the health centers at all. I think we are missing out on a great opportunity to create something really, really good for patient education and you know for … to provide a different type of case management that is more interactive and more engaging.

A patient navigator at another health center recounted a long struggle for recognition.

> we're just seen as outsiders. I mean, for one thing, we've since moved, since it's actually been much better. But, I think, since we're, like, not a part of their group and we don't have all of the same supervisors and things like that and for a long time, nobody really understood what we did and we kind of got in people's way more than anything else, and I don't think people really understood, like, why we were helpful or anything.

While most program directors lauded its holistic health approach, those at more rural locations also noted some difficulties with realizing fully this approach. One said that psychologists and other behavioral health providers were not available through the program and that it should fund counseling for those who receive positive cancer test results. The Program's inclusion of undocumented immigrants was mentioned as a "huge benefit," but one program director explained that more funding was needed for services required by these patients after they received a diagnosis. Several directors noted special challenges associated with the "Healthy Heart" program, with special assessment and follow-up requirements. Improved connections with other health care organizations had helped to lessen these programs in some non-comprehensive smaller clinics.

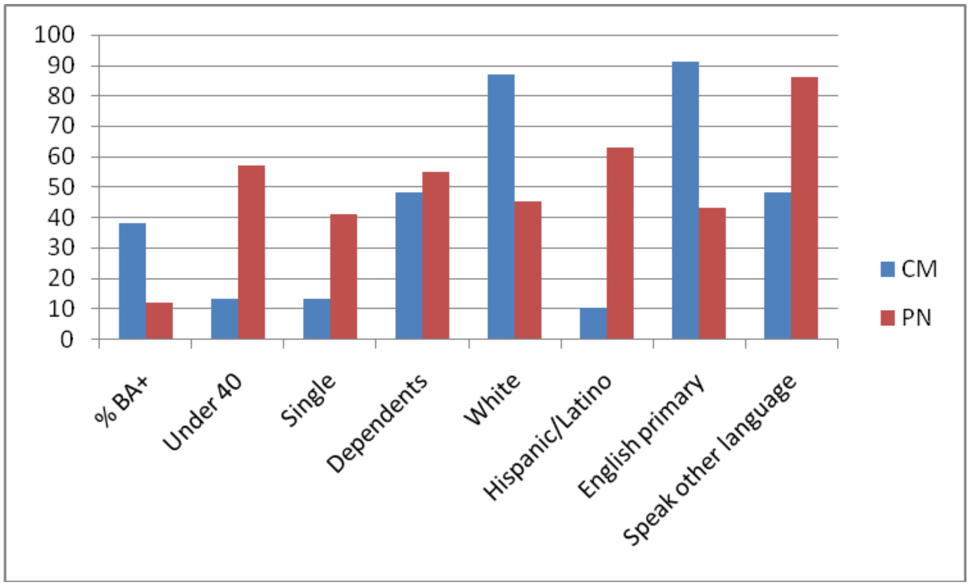
Care Coordination also increased emphasis on data collection and tracking outcomes. This experience had not been entirely successful, as there were many complaints about the inadequacy of the database system required by DPH as part of the Care Coordination Program. Some of the larger centers had developed their own system to keep track of program patients, and all were relieved that the original DPH system was being replaced by a new one. One director felt outcome measures were needed to track patient change over time (the DPH database only gathered medical data about cancer tests).

Social Background

The social backgrounds of patient navigators differed markedly from those of case managers (Exhibit 1). Only ten percent of the patient navigators had at least a BA, compared to 40% of the case managers. The patient navigators were much younger, more often single, and less often white. Almost two-thirds of the patient navigators were Hispanic, compared to just 10% of the case managers, and English was the primary language for one-third of the patient navigators. About half of both groups had dependent children.

Exhibit 1

Staff Social Backgrounds



Training

Almost all case managers (95%) and patient navigators (92%) reported that they had had special training for their job. However, reports of specific experiences varied widely. One case manager remarked on the value of centralized DPH training.

> the program manager was a really good mentor and teacher umm but besides that we had a large number of trainings with DPH that were ongoing and we had reinforcement through team meetings, provider meetings that DPH held along with follow-up trainings. We also interface with them on a pretty regular basis.

Another case manager supplemented DPH training with other conferences.

> DPH meetings really helped me out with that, you know, the quarterly meetings and I did a lot of reading and research on my own. I'm still to this day doing research and I read and go to conferences, you know, I go to breast conferences, I go to cervical conferences, I go to diabetes conferences. A lot of this is out of my own pocket.

A patient navigator appreciated the centralized DPH patient navigation course, but found that training at her center and through on-the-job experience was essential.

> I would say I learned a lot on my own. The navigator course was helpful, definitely but it was less, it was more kind of general, so it, you know, I would say learning here was more practical, you know, about our specific, the way we do it here and there it was kind of, and with the navigator course, it was more general. But, a lot of the practical stuff I learned kind of on my own.

Patient navigators often emphasized the importance of learning on the job.

according to your position, they teach you all the tools that you can utilize and I feel that you learn by just jumping in. there is no other way. Also there's no way to tell you all the things you are going to see. There's a standard. It's like, colonoscopy. Yeah, referral. Yeah, order. But, reality is since you're dealing with people everyday to different case and a different situation and so it's, you have to learn by, by doing it, I think.

it went well. I did a lot of shadowing and observation and umm seeing how things function at different clinics. How the outreach, umm, you know, how that takes place, how it’s done, umm documentation, how to…uhh, you know all that comes along from working from patient lists, umm, you know learning about the different screenings and what’s important and you know, you know what’s the recommendations for these, you know, for certain patients so forth. Couple weeks and then I moved to the health center and met with the staff and then with the providers, one on one and just started working from there.

I did a day shadowing everyone in the health center from the front end to the outreach coordinator to the team nursing, NAs, providers so I spent half a day to a day with each of the staff members to kind of see how the work flow was. …I did a training for lifestyle self-management for our diabetes patients…. And then I just did a lot of reading on our grants.

On the job assistance also helped new patient navigators develop a culturally sensitive approach to groups with which they had limited experience.

> the Brazilian population, so I did have to learn about their culture and their level of respect and they expect from us and you know what we should expect from them. … the person who trained me is Brazilian, … I realized that you have to know the person before you try to jump in and try to help the person, because they might not accept this as well as if you know, you are culturally sensitive to them.

Training on the job could also build a sense of team support.

> the trust they had in me, they said you are here to learn, we are not going to judge you, you came here to learn, we need you and you need our help so we need you, so from the beginning they were caring and they made me feel…I didn't, once feel "Wow I don't have enough experience" They taught me and watching them they taught me – and I learned faster because of their sympathy, because of their care, they didn't teach me because it was mandated, they were teaching me what it is like to be here, what you do you have to love you have to feel empathy for the patients, you have to feel good and that's how they taught me.

For some patient navigators, such training had been primarily self-initiated.

> With actually this program, no, I just took the manual and read everything I needed to know and from that I basically did the program and I'm doin' the program. It's pretty self explanatory, most of it, and the forms are very easy umm I haven't had problems yet with interpretations on anybody.

Supervisor engagement could also be critical.

> Now, see, my supervisor, she's always been very supportive and willing to answer questions and making sure I understand how everything works.

When staffing was cut, training for other functions also became critical.

> I had some training with one of the other risk reduction educators, a lot of the other stuff was sort of just on the job training because some of the stuff just happens and you have to figure out how to learn how to do it especially with all the budget cuts at the last round everyone has to do everything now. So I just sort of learned how to call people using an interpreter originally I just did risk reduction with the English speaking clients. Now with such little staff everybody has to do everything so you have to learn on the job training. But DPH has been really good about educational programs and training and that has been really helpful.

The statewide patient navigator conferences organized by the Department of Public Health were viewed by many as very worthwhile opportunities to learn about new developments and share experiences, but some did not view them as actual training sessions and felt they did not provide enough opportunity for audience participation.

> That really wasn't a training, that was – it's like a seminar, that they have every year and were the people that work in the program have to go, it's really not mandated but it was suggested that we should go, where they will talk about everything, for example colon cancer, and rectal cancer, where they talk about different topics, where they talk about the program, it's very vast it doesn't just talk about something particular, like the training that they are giving you can choose what you want particularly. That last one was very vast and had a lot of things, a lot of things that really I can't remember all.

Case managers often reported effective training on the job.

> I got training with one of the other nurses who does a lot of the care management for other clinics. She is a part time person, but she does a lot of per diem, so she was really, really good also J, who is the director here of plan care, I've had to call her on occasion and she is always very, very easy to talk to, we meet monthly … I would say it's pretty well supported but you know, it's difficult, like I said to find the time to do it, with all the other nursing things that we have to do, and it's not on the top of my radar.

Prior work experience provided a foundation for the success of many case managers.

> I mean a lot of it was transferred from my prior job because I was doing the same program that was sort of transforming itself over years and adding to it so I was always doing it so it would be adding to what I already knew the … systems and a different population and well it was different but it's like taking… like knowing what to do and then having to apply it to a new structure.

But case managers were also more likely to report a lack of comprehensive training for their Care Coordination job than were patient navigators.

> Special training, not really. I mean I was trained by people that went through the charts and showed me what I should be doing but I never, you know really trained on how to be a case manager. …I mean now I know what I am supposed to be doing and I know how to look at a chart, but initially a lot of the functions I have to do I had to learn because I am not medically trained so I didn't know about blood pressures and A1C and none of that stuff.
>
> There was no training, when I came in the program had already been running for two years and they said there were no computer trainings so basically I created my own tracking sheets. I learned Excel by asking a lot of questions to our computer department and saying I don't know how to do this. I have the nursing knowledge, I know what I am looking for, how can I do a database that can

> help me track this for the program and pretty much the girl that works there said, “what are you looking for?”

It is therefore not a surprise that both case managers and patient navigators felt additional training would help, with approximately half of both groups feeling it would help “a great deal” and only about one in five feeling that more training would not help very much (Exhibit 2). For some case managers and patient navigators, support for more training reflected a general commitment to the value of education.

> Do I always think that we can do better and more? Yes. Can I do better or more? Yes. So, do I think that, you know, training is a continuous process? Yes.
>
> I think there’s always room to learn.

Exhibit 2

Helpfulness of Additional Training by Job

		job		
		case manager	pat. navigator	Total
additional training help	A great deal	54.5%	44.4%	49.0%
	Moderately	22.7%	37.0%	30.6%
	Not very	22.7%	18.5%	20.4%
		22 100.0%	27 100.0%	49 100.0%

> I feel I need to learn and I am going to keep learning because I never feel I know everything, there is always – I learn from the little ones, to the biggest ones , I learn from the patients, from you, I learn from everyone. So any training that might come, any training, or any orientation will be needed. No orientation will be unwanted, everything will be needed, I believe you have to keep learning always, any training is fabulous for me, because when you are trained you grow as a person and when you grow you can help your patients, your home, it helps you with everything.
>
> you can always get something out of training even if it is really boring, but there is always something new so it's never going to be the same thing over and over and over for ten times there is going to be something improving or always something changing, so I think as many training as they give I am willing to do it, I'd be happy to take it.

Some were more specific in the training needs they described.

> I mean, I know how to navigate a patient through the system, you know, and how to make appointments and all that stuff and get transportation. Yeah, I know how to do all that stuff but officially in that role, you know, I'm sure I could figure it out but I haven't had the training, no.

One case manager suggested statewide interdisciplinary and participatory meetings to share and problem-solve.

> I think that it would be helpful if all of the case managers and community health workers could gather in a way that we do not now and what I mean by that is now we have quarterly provider meetings where we meet with the state. We don't really work with each other and I think it would be so beneficial to have time to chat things out with people about the actual work, not about are we meeting our numbers but to really look at okay, say for example you're working with a young woman – 21 year old woman who is Brazilian and she needs follow-up for abnormal paps. How do you capture these people? How do you get them to come back for that six-month follow-up pap after a colposcopy? How do you keep them from falling through the cracks? How do people from a more urban setting deal with that as opposed to a more rural setting like we have out here on the cape? But you know, there's rural settings out in western Mass. How are they dealing with that? I think it's such a rich opportunity for people to chat out how different people do the work and I think that would help.

A patient navigator emphasized the value of focusing training on issues facing specific patient groups.

> when we went to the refugee health training, that was definitely helpful but because even learning about, like, the process of how refugees come to this country and, like, legal issues and health issues that they face, you know, that you wouldn't know about.

> Unless you were kind of, like, in that world or really directly involved in it. And we have some refugees here but I don't really know what happens. so, so, that, that was just an example, I guess, of a good training. Or, you know, kind of, like the—for me, I like learning about, kind of, like, specific things. …maybe learning about specific cultures or particular things to, like, look out for when you're working with Haitians or West Africans or whatever. like, particular issues that they face, and. What was I gonna say? Or, like, some of this, they have at, like, the patient navigator training but, like, mental health and, like, how to work with somebody who's bipolar or schizophrenic.

Patient navigators also recognized the value of more training on specific medical issues.

> any type of training that is related to something in our role, example like anything related to diabetes like DHP did last time. I really thought it was great. Any sort of training on colonoscopies, mammograms, you know any sort of appointments that were involved I think would be a good training for any navigator at any time. There is always something new, it’s always improving I think, it’s always great to have updated stories on it. So I think it’s whatever is included, … I think mainly we should really focus on the programs that we use and everything that we offer as a navigator.

Work Roles

The work of patient navigation revolved around phone calls with patients, and then with others about the patients' needs.

> A day has a mix of a lot of things, I beginning by reading phone calls. For example, let's start with today, so today I called, I received a client's phone call who I had left a message for to remind her that her mammogram was overdue, her physical, her Papanicolau, and she called me back, very sad because she had serious problems with her daughter. Her daughter was hospitalized, serious problems, so she asked me for totally different help, that is very common in our program, which supposedly is breast –cervical and breast prevention y you know the healthy heart lifestyle changes and all this stuff, but you encounter like this one where they need help from a social worker; did they call the police? Can you tell me if my daughter is eligible or not for insurance so for example today I helped her by giving her all the information on how she was eligible according to her current situation for the Mass Health insurance, I made the connection with her and Mass Health so her daughter would be covered, in order to be convinced that she was covered that she has a right to by law, because she is a minor. I gave her the social worker's numbers and gave her some information of some groups in the area she leaves in. She asked me to help her with a… a medication, with a prescription that she lost

so, how… we called the health center directly to see – to leave the information…so that for example was today, a phone call like that could be today and nothing like that would happen until two or three days from now and when it comes up it falls completely out of the program but it is a client that needs help and we need to give it to her as much as we can. And then other calls from clients that leave information of which days are better to set up appointments, another phone call might be to call what is their result so I'll make the connection with the clinic. After checking all of my messages and returning phone calls I'll check which clients I have to enroll in the – the information in the computer, so new clients, enrolling is a long process, because it's all the demographics, after I have to do the history, family history, medication history from clients, which medications are they on and later all of the questions of where they are right now – what is their status for appointments and screenings. After collecting all this information, I have to look at the Healthy Heart part, filling out the Healthy Heart formats, Risk Reduction Education and after filling out those formats, I fill out our computer database, what we still call Women's Health Network Database and after that information goes in the Department of Public Health program, which is family history, enrollment form and Healthy Heart. All this information goes in there, so I do enrollment. After I'll go through all, on the calendar I check to see more or less who – I check those who should've gone to different appointments like mammograms, physicals, Papanicolau and I check if they did go and I help the nurse get those files so she can ask for results and fill them into the system. Also with the phone calls, we check them through the different months, the nurse will check the different months in an alphabetical file we have since we are not directly at the sites, we have a copy of the records, what refers to us, so for example we check April right now, who are overdue this month, so she gives me the five of them, six, seven, ten files and I during April, "okay Maria Perez, your mammogram is overdue, and last month your Papanioculau was due." And I start making phone calls, those are all mine, in Spanish, I leave them a message or if I can talk to them I make the appointments right away, I call the hospital, Metro West Medical Center, with the person on the phone, we make an appointment for the mammogram, we then cancel the call and move on to the clinic, I need an appointment for the Papanicolau, I call there directly and that is the most difficult, communication with health centers; with health centers there is a lot of wait, a lot of waiting and many times they don't answer, it's really difficult, the mammograms are simple, so that takes a lot of time. After all of that I start working with, I help the Portuguese girl I try to – I am learning a little bit of Portuguese, so I'll call those that are less complicated cases, ones that don’t have…just the basic, ones that don’t have a lot of problems like abnormalities or questions on the results, because results are easier in their language, so those that are simple I will call them and you need, okay “Vusa fala Portuguese?” and da, ta, da, ta and so I can practice my Portuguese and I do…and I help the girl because the majority of our clients are Portuguese so I work and I help out the girl that works with those clients, I help out with the less complicated cases and I do the same process I just explained to you but in Portuguese. That’s my day.

Usually I come into a lot of phone messages and medical record messages from patients from the phone and providers in my messages so you know, I haven’t even taken my messages off the phone yet but I think there are twelve. They are all patient calls. They are either weekly check-in calls ‘cause people check in with me or they are people calling for assistance. The provider messages could be anything from patients needing lifestyle education to an identified resource need that occurred during an office visit when I wasn’t on the site because I was off-site yesterday. So, I try to right away respond to those. I keep a notebook, a paper notebook where I just journal everything so that I can follow-up through the day when I have time to and I prioritize those obviously, our provider messages are usually my first response and anytime I do a contact with a patient for a provider I do a progress note, a case management progress note in the person’s chart and message the provider. A typical day… so that’s probably my first half-hour to hour in the morning is prioritizing messages, checking in on those for the day. Depending on the day of the week, I mean, I have a lot of other things I do, I run some groups and umm, I’m trying to think… a typical day? There really isn’t a typical day. I’m available to providers. If I’m available at my desk when they’re there with a patient that has a particular need, you know, if they can’t take care of the patient because they’re… this week we had someone losing their house in two days, she couldn’t afford her medications and she was just sobbing in the office and he couldn’t even take care of her and I happened to be sitting there and was available, you know, they come and grab you. When you’re not available they are very frustrated but there is a case managing nurse and myself and we kind of work very closely together so I’m very fortunate except she’s leaving in a week so I’m a little worried about that. So, basically responding to the needs of patients, anyone from the front end at registration that identifies something, a team nurse that knows someone that they have that is in need to the provider, they try to get us at the point of a visit. A lot of times we have certain patient panels that we know are coming in I pull a couple of reports, like a diabetes report because I’m responsible for those patients so I kind of know certain people that are coming in or I'll take a look at providers' schedules and see if there is anyone that I need to be checking in with for the day. So, I might have four or five encounters in a day, I might have twelve encounters in a day depending on who is here and what the needs are. Our providers will often send a red message if they have someone in their room right at that moment to see if I'm available so if I'm at my computer and I see them I'm able to go just check in. Twice a week there are two providers here that I meet with to do case review on patients on an ongoing basis. Not all of the providers have asked me to do that and I'm kind of glad because there isn't really time to do that where we just check in on a group of patients that are really compromised and really need weekly check-ins, weekly goal setting, weekly action plans and care plans put in place. So, a lot of it is triage-y, in the moment and other parts of it are kind of well planned. Once I've established with a patient I usually set up that I phone them the first week to check in, you know if I've given them a task or two to take care of and I'm doing a task or two. It's always about self-management and trying to get them to engage in something they can do. I've learned to not work harder than my patients which is a challenge and so I will make the first week call and then after the first week I encourage them to call and check in with me on a weekly basis otherwise I would have calls forever, you know? And so that’s what probably the majority of those calls are they’re patients checking in and saying, ‘I called housing, I found out that I can’t reapply for a year or there is a three year waiting list for the voucher,’ or whatever and then I’ll call them and they give me a best time to call them and that way I’m not playing phone tag back and forth. I always ask for a best time. So I do a lot by phone, a lot of it is by phone after we first meet. Sometimes I do a lot by phone and then I finally meet them months down the road if they’re at one of our satellite sites and I’m never there when they’re there, with transportation being such a challenge where we live here phoning is often the least expensive way of offering assistance and mail, I mail a lot of things to people. So a typical day… today we have a shared medical visit in this room so we’ll have ten patients in here for their office visit and it’s a diabetes one so it’s patients who are considered either poorly controlled or patients that need the social or other resource support that this group could provide. I was looking at the panel of patients and several of them are our grant patients as well. So they are in financial strife so it will be an opportunity in that shared medical visit to do some work with… we have a behavioral counselor in here and I’m in here as the educator, navigator, however you want to look at it so there is an

> opportunity for shared resources among patients but also where I can do some educating.

Case managers' work focused more on patients with abnormal test results, but like patient navigation also often revolved around phone calls.

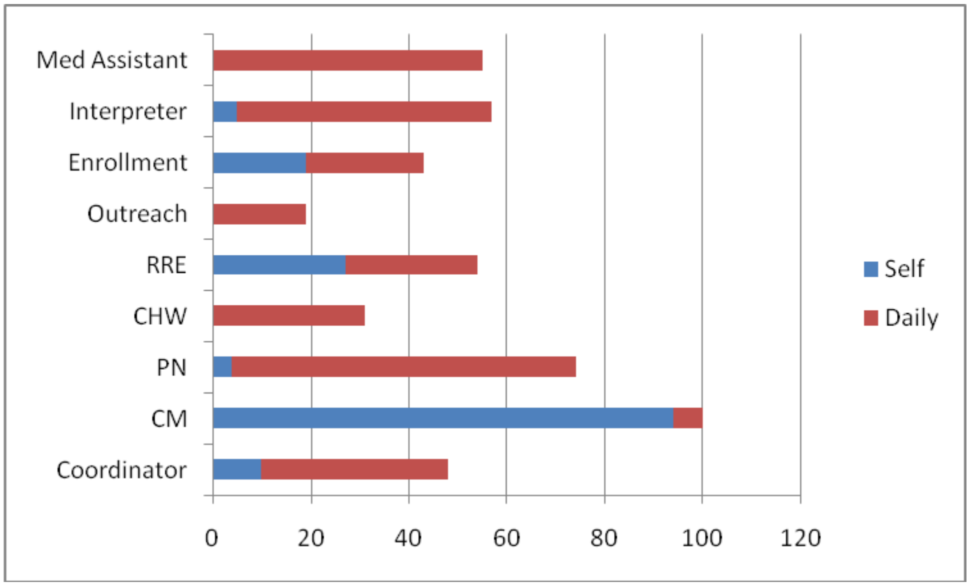
> Once I do the chart review I figure out what are the best referrals for the patient. So then I have to do a case management note, in which I will go through the same fields and then that's when I am supposed to interact with patients and you know discuss if there were any abnormal findings, what the plan should be. But to be honest with you, my contact with patients is very minimal because we are supposed to be doing this over the phone. And, I usually do the chart reviews but I refer staff to call patients to schedule appointments.

Both case managers and patient navigators tended to have more than one job in their health care organization, with this being slightly more true for case managers (64% had another job in the organization) than for patient navigators (52% had another job in the organization).

Case managers were actively involved with other health care workers. About one in five served also as enrollment specialists and as risk reduction educators (Exhibit 3). In addition, about half were in daily contact with medical assistants, interpreters, patient navigators, and care coordinators.

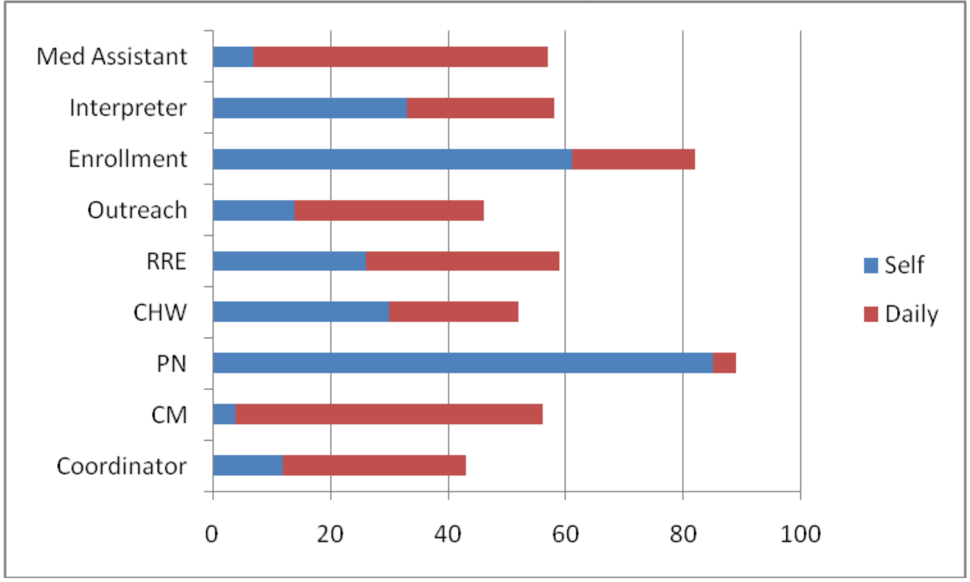
Exhibit 3

Case Managers' Work Roles



A majority of patient navigators served as enrollment specialists and about one-third also served as interpreters, risk reduction educators, and community health workers (Exhibit 4). Patient navigators also had frequent contact with medical assistants, outreach workers, case managers, and care coordinators.

Exhibit 4
Patient Navigators' Work Roles



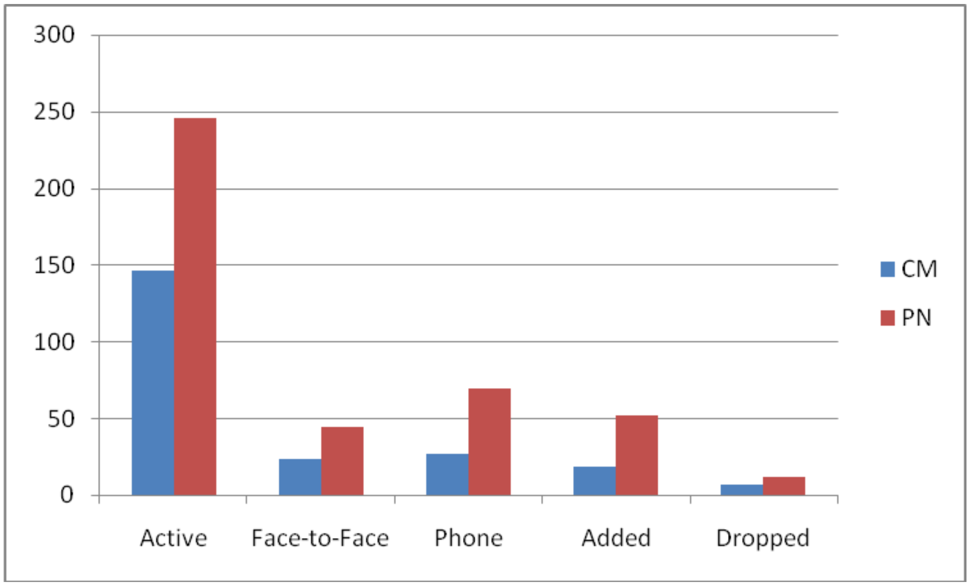
The Patients

Active caseloads were high for both groups, with patient navigators reporting about 250 active cases and case managers, 150 (Exhibit 5). However, the average number of patients seen each month was much lower, with patient navigators speaking to about 60 each month on the phone and seeing about 40 in person. Case managers reported phone contact with about 20 on the phone and about 20 face-to-face. Patient navigators added about 40 new patients each month and case managers about 20, but neither group reported dropping many patients from their caseloads.

These high caseloads were often a source of complaint from case managers.

> the size of the list of patients that I have to manage, it's very, very hard to be able to complete the chart review right away and do the appropriate follow-up so it's… I know – I think DPH wanted us to get that done within three months but it's impossible

Exhibit 5
Monthly Caseloads



The workday for case managers often began with a review of test results about patients on the caseload.

> …the only option I have because the programs are not together is I have to open every single chart, so this is what I do every single day. If you're lucky you might make it to twenty-five patients a day, twenty-five – thirty patients because the problem is it might give me the date of when they had the mammogram …but I can get into the hospitals records and print out my own copy before it arrives here, read that, decide if it's a normal or abnormal, put it onto the tracking sheet and I do this for everything that's on that patient.

Patient navigators often began their day by reviewing a list of patients due for appointments.

> when the list comes, it comes and we know that the patient didn't come in other words didn't show up for an appointment, we take a look and see that the patient needs a physical or the mammogram or didn't show up for an appointment, so that's why they didn't … and if it's an enrolled patient, well automatically we do follow-up, we can see. For example if a patient comes today, then the patient comes today and I automatically open the APN and I can see if that patient didn't come for his physical, Can I help you, what is more convenient? Or you didn't come to your mammogram, 'Oh, yes I am sorry' or whatever and we follow them. But automatically it's a

> list we receive every day, when we get in we have to print it and from there we see the amount of people. For example on a Tuesday if there are three doctors, each doctor has – has twelve-fifteen patients who we have to do follow-ups for but since that’s a lot, for quality purposes we have to select which are priority, what patients need, for example if there is a patient who is much sicker obviously is going to be priority over a patient that isn’t as sick. So we focus on that.

Others were notified of patients to check with a computer program.

> I find out through an IT program, which sends the program so we check it every day, or where we have right now every person. Each has a number of patients assigned, we provide their follow-up and which are their priorities according to their age, so that’s how we find out and we follow that patient.

Both providers and patient navigators could initiative patient engagement.

> if the patient is new to the clinic, we will know 'cause I go through the schedule everyday, almost everyday. So, that new patient, after they see the provider, they some time for screening, any type of screening I will encounter that patient. 'Cause they will send it to the navigator board. Oh, that patient needs risk reduction education. The patient needs a mammo scheduled. The patient needs a colonoscopy. All these things, so, I will have to help the patient schedule, make sure the patient have everything she needs.

Patient action was also required for effective engagement.

> I call the patients. Like I said, I go through the schedules and I look and I'll call the patients and offer them what we have, tell them what we do and if they're interested to stop by and see me and a lot of the times, they want to speak with their providers before to make sure it's okay and the providers a lot of times will just have a, send me emails, messages, you know. This patient would be great for your program. She needs this and this and this and that. You know, so it's word of mouth. We have our flyers up. We have, you know, the providers are, are mainly the ones, the source.

Establishing a friendly style of engagement was essential for effective social interaction.

> we interact then and then I, I let them talk to me. Some of them keep me in a room for a long time. So, I think we get a little bit—some of them share their history with me. Some of them even tell me about their kids. Like, this is them one day and, when I see them again, they're happy. They smile at me and I smile at them. So, I think it's easy for me to interact. I don't. I think it's fine. I try to make them comfortable, like, you know?

The initial contact with the patient could then lead to multiple follow-up actions by the patient navigator.

> usually it requires a phone call to the patient, so I can make sure I am understanding exactly what the patient is needing or the entire

> situation. Once I do that then the ball starts rolling, whatever it maybe, I will make the phone calls, the necessary phone calls that will, that will hopefully assist the patient or if the patient needs to come in for anything, or if the patient needs to see the social worker because they have something to do with this paper work that is way beyond their….or if it's in English and they don't understand, umm I will schedule an appointment with the social worker. If the patient is not feeling well, I will contact the doctor, maybe depression or whatever, it depends on what it is it could be a number of things, but if it's can be medication, they can't get their medication because of money or they lost their medication, contact the doctor or because of money then I have other resources that I can turn to make sure that patient has the medication or whatever is needed.

Patient navigators and case managers described their Care Coordination patients as poor and either unemployed or working multiple low-wage jobs.

> A lot of them generally have two and three jobs, home making, hair dressing, cleaning peoples' houses, under the table work unfortunately. A lot, you know long hours, very physical, it's pretty draining for them to think about starting something new in their life.

> Majority of them are cleaning, they do cleaning, the women here, a lot of the men do work in restaurants, will work umm painters,

> that's a good so they work two jobs generally even on the weekend, so it's hard to have them come in cause you know their immigrants, it's hard for them to come in for appointments because they don't have vacations, they don't have time to take off from work, so missing a day they could lose their jobs, so it's just that's the typical… and they work, like I said they work two jobs, and they have families, they have kids, it's just tough.

These multiple jobs in turn created problems with receipt of health care services.

> A typical patient, is always on the run (laughs) always rushing, that's typical, rushing, 'I am working I don't have the time', 'Oh, I forgot my appointment', 'Oh yes, I am sorry I forgot, can you make it again?' (Laughs) That's, mmm, but it's not all the time, it's very typical because the group of patients that we have, has a load, they have long hours, especially Brazilian. They have long hours so if you call and you are trying to talk to them and the vacuum cleaner on the back going, so they are extremely busy and most of them work in house cleaning and they have – immediately they ask if you can call them back at six. So our typical patient is very busy and yes…and, but is very grateful for the service we provide them, always very grateful, most cases give us very good feedback of what we do and they are very grateful for the support we provide and they do express the same frustration that they can't communicate with the health center directly or that their schedule

> is difficult to coordinate, so – but no, it's…like…what else can I say about a typical patient? They talk a lot, they talk about everything, aside from…that's not the typical, sporadically you find one that will tell you a million things, mostly those that don't, those who right now don't have a job, they have all the time in the world….

Patients were often immigrants, although their immigration status was kept confidential and did not affect program eligibility. Many languages were represented among the Care Coordination patients. In addition to English and Spanish, there were many Portuguese-speaking patients, but also some who spoke such languages as Haitian Creole, Thai, Vietnamese, Russian, Albanian, and Ghanaian.

> I'd say probably half of my panel might be Spanish, the other half would be mixed, Portuguese, we have a lot of refugee, well I wouldn't say a lot but in that other mix there's some refugee, different languages. Most of them are unemployed, a good majority takes the bus here, a lot umm have a diet high in carbohydrates because the access to food is not as available and the financial constraints. I'd say that's the typical group.

Immigrant status could explain the low-wage work of some patients.

> In their country a lot of them surprisingly many of them are college educated but because of the language, because of their illegal status they end up doing painting or house cleaning or things like that but some of them are very educated in their countries.

Patient Needs

Case managers and patient navigators identified both their patients' service needs and the difficulty they had in meeting those needs. Specific needs were grouped into the areas of health, psychosocial, practical, and communication.

Health Needs

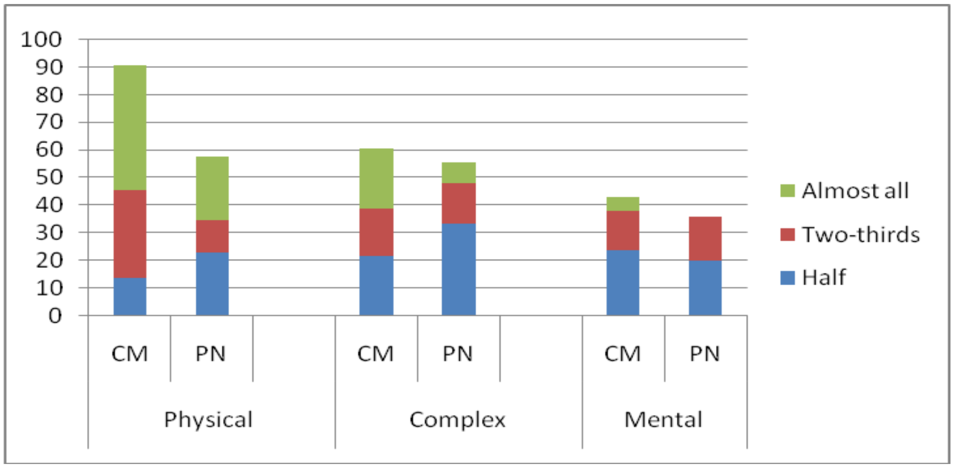
Almost all the case managers reported physical illness as a major need for at least half of their patients, with almost half of those identifying it as a major need for almost all of their patients. Patient navigators were much less likely to have patients with a specific physical illness—fewer than 60 percent reported that at least half of their patients had a physical illness.

> it's a mix we have a lot of patients, a lot of patients, you know, who are obese, a lot of patients with diabetes, a lot of patients with hypertension, a lot of it is related to the diet too, the culture here

Case managers and patient navigators did not differ much in the number of their patients who had complex medical problems or mental illness and both problems were encountered less often than was physical illness (Exhibit 6).

Exhibit 6

Prevalence of Patient Health Needs



Case complexity was often associated with poor outcomes, as a case manager explained.

> A man who I spoke to on his blood pressure was really sky high, it was a young man who was admitted to the hospital for hypertension crisis, he was also a drinker and a smoker, he had a lot of problems. I remember nothing sunk in he wasn't taking his meds properly so that I felt was a loss on my end, he did not follow through. I mean that's exactly how I felt that our interventions didn't help and he was back in the hospital with hypertension. …he had so many red flags. …I could never reach him. …They come so often, the psych patients, the alcoholics and such, if they're going to drink and smoke and everything else.

Patient navigators approached these different health problems holistically, adjusting their attention to one problem in relation to the importance of others.

> Well, if, let's say, with physical problems, I try to make sure that they have transportation, aren't doing too much at a time. Have plenty of time between appointments, if they kind of move around slowly. Complex medical problems, I try to make sure, like, people, kind of ask people about if they're up-to-date with all their specialists and things like that. Kind of talk to them about if they have any urgent issues at the time and if they do, we tend to put off the mammogram, things like that. I mean, we definitely have people who we've—questioned if they really need to have a mammogram right now, if we should do it later. Mental illness,

> with some people, I've tried to hook them up with behavioral health or make sure they're getting in smoothly 'cause it's kind of complicated here. In terms of contacting them, it depends. I f it seems like somebody, somebody's mental illness, if they're something like that, if it's not very under control, I might not actually call them. I may try to meet them in person, make sure they know who I am or kind of consult with someone about if it's, like, appropriate to meet with them or not. I try to help people complete forms if I know that they're having trouble with something in particular.

Of course, the particular types of physical health problems on which case managers and patient navigators focused differed, as did the services they provided. A patient navigator explained.

> I get to work with different patients with different types of diseases. I may have a patient—I may have four patients with only diabetes, high blood pressure, and breast issues and I may have a list including everything. So, the only thing with abnormals, I do not work with them. The nurses [case managers] take care, take care of abnormals. But, I did, if the patient needs an appointment scheduled. Yesterday a patient needed a ride.

Case managers had to deal with the difficulties associated with fears about cancer and cancer diagnoses.

> a diagnosis of cancer is overwhelming; your whole world is out of control and they are very, very happy to know that they have a team working for them, pointing them in the right direction, getting things done on their behalf.

On the other hand, case managers also often dealt with the many interrelated aspects of patients' health problems.

> Education, links to different resources – both around her diabetes, weight loss, smoking, you know, around the physical things – connected her to a walking group, gave her information as she was ready for it, about smoking. She's tried off and on to quit smoking, but mostly just offered the structure of being able to meet her on a regular basis.

A patient navigator described the medical complexity of some cases:

> Oh yes, I have this patient with breast cancer, with partial, she just had a surgery with partial mastectomy. … she was alone with her daughter and without insurance and a lot of complications, because her lymphedema was affected, it affected her hand as well, so she was handicapped she couldn't work for her children's … she lost all contact with the health center, … in the hospital she wasn't assigned a social worker because she preferred it be in her language and she wasn't going to have any benefit from that. … she has Mass Health services and has transportation through Mass Health which was another problem she had, we had a girl who

> spoke her language who came with her to all of her appointments and I got her additional medicine which she didn't have to pay, so free meds. And I got her physical therapy for her arm which was affected by this, and now we are looking to see how we can help her with the food and how to survive, her and her daughter because since she hasn't been working for this period, it was like bouncing back, Oh, my God. Five to ten different people and no, finally we achieved our goal. She calls me quite often and tells me I was an angel with her because she was in a very desperate situation

Although they were perceived as less common than physical illnesses, depression and other mental health problems added to the complexity of patients' service needs.

> Mental health complications are very difficult because the mental health system is historically behind you know there are always a few months for people waiting to see them, …there is a high percentage of depression with the immigrant population and the economy and everything that is going on today.
>
> depression is pretty prevalent I mean specially if they are dealing with unemployment in any way, I mean it's the social circumstances and a lot of women, even though they work all the time and everything they're fighting, they are very isolated.

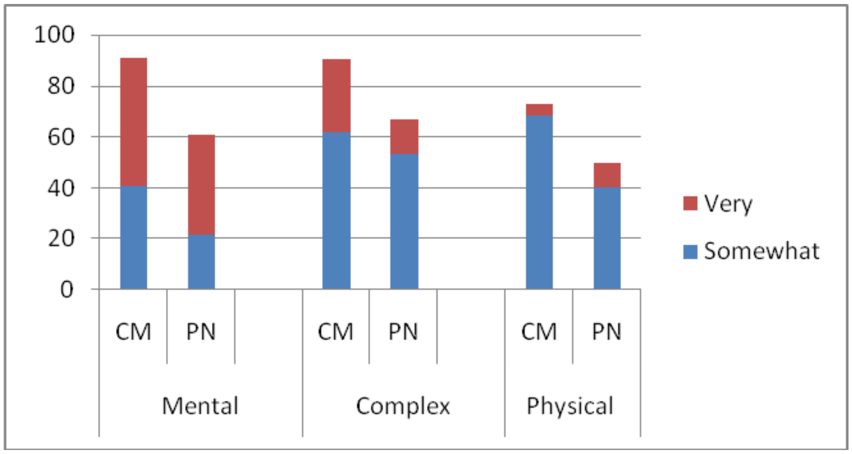
Patient navigators connected some of the mental health problems to immigration status.

> .. a lot of our immigrant population they are depressed, being here not speaking the language and not understanding the health care system here it's pretty difficult for them, so…

Patient mental health needs were rated as very to somewhat difficult to meet by almost all case managers and by most patient navigators, as were patients with complex health problems (Exhibit 7). Patient physical health needs that were not considered part of a "complex case" were rated by both groups as less difficult to meet.

Exhibit 7

Difficulty Meeting Patient Health Needs



Many patient navigators and case managers found that their patients were very satisfied with the health care they received. Patient navigators themselves were the object of some of this patient satisfaction.

> most patients are very happy when you have someone that can help them understand things that they've never seen before you know … so they're very grateful that we take the time and they thank us very much, especially the Latin population, they are very, very grateful because I don't even know if they have those services in

> their own country, so coming here and having someone take them by the hand and helping them through all the steps, their very, very good

The perceived patient gratitude extended to doctors at the clinics.

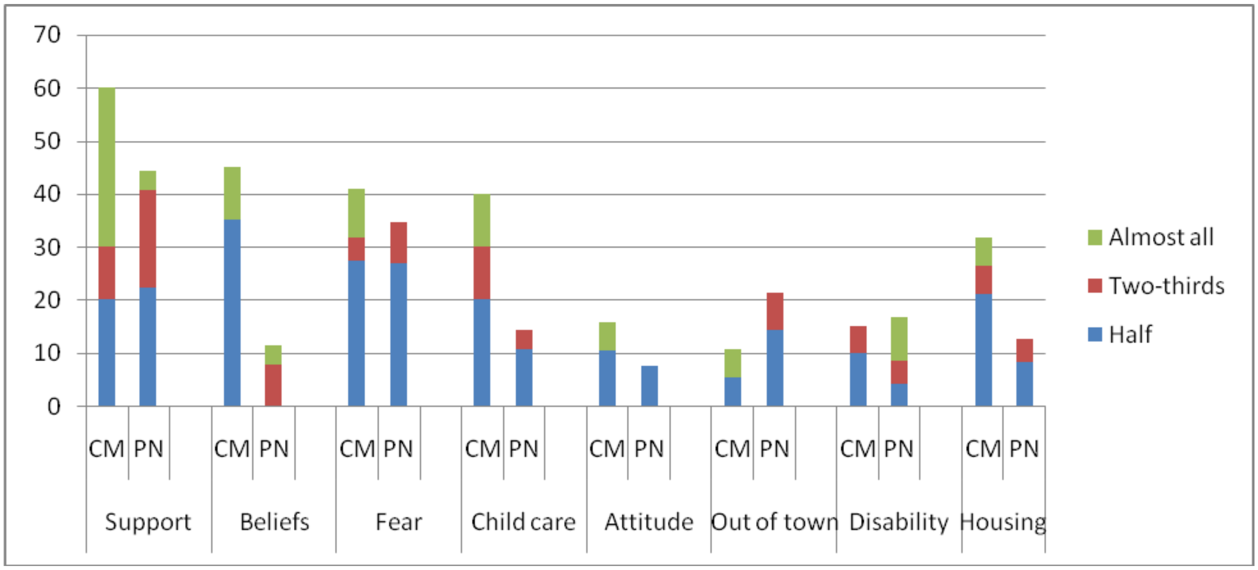
> I get it all the time from patients, they always tell me how much they love their doctors and 'I wouldn't switch my doctor for the world', so I don't know what these doctors are doing but they are excellent

Psychosocial Needs

Several psychosocial needs were common among patients, with usually similar prevalence rates reported for patients seen by case managers and patient navigators (Exhibit 8). The one statistically significant difference was that more than 40% of the case managers reported that at least half of their patients had problems with their beliefs about tests or treatment, but only about 10% of patient navigators reported that these problems were as prevalent among their patients. Concerns about child care were only slightly less common. Between 40 and 60 percent of the case managers and patient navigators reported that at least half of their patients had social or practical support needs and between 10 and 30 percent of the case managers and patient navigators reported housing as a common need. Fear was perceived as about as prevalent a need among patients (40% found it among at least half) by case managers and patient navigators. The other psychosocial needs—attitude toward providers, being out of town, and disabilities—were much less prevalent among patients of both case managers and patient navigators.

Exhibit 8

Prevalence of Patient Psychosocial Needs



Patient navigation often involved a mix of efforts to connect patients with doctors for medical services and with other providers or services to meet psychosocial needs.

> I contact them and try to get them to see the doctor. I sympathize with them, I really do. I try to connect with them according to their culture. I’m very culturally sensitive. I try to find outside resources for them like you know, I spent some time calling museums and asking for free passes and I’ll continue to do that for the patients. We have vouchers, we are very fortunate, we have some cab vouchers for the patients. If they really can’t see the doctor there are rides… I hook them up with the social worker or case manager if it’s a problem that I can’t help them with, like housing, I don’t know what to do for that but the case manager does.

Case managers also responded to the grievous support needs of patients suffering from cancer.

> she had just stopped her chemotherapy for her lung cancer because it only had a ten percent chance of working and the side effects were unmanageable; no food in the house; nothing to hydrate with; no money. I applied to a fund for her and got her some grocery gift cards so she could get groceries; linked her up with a support group; linked her up with hospice.

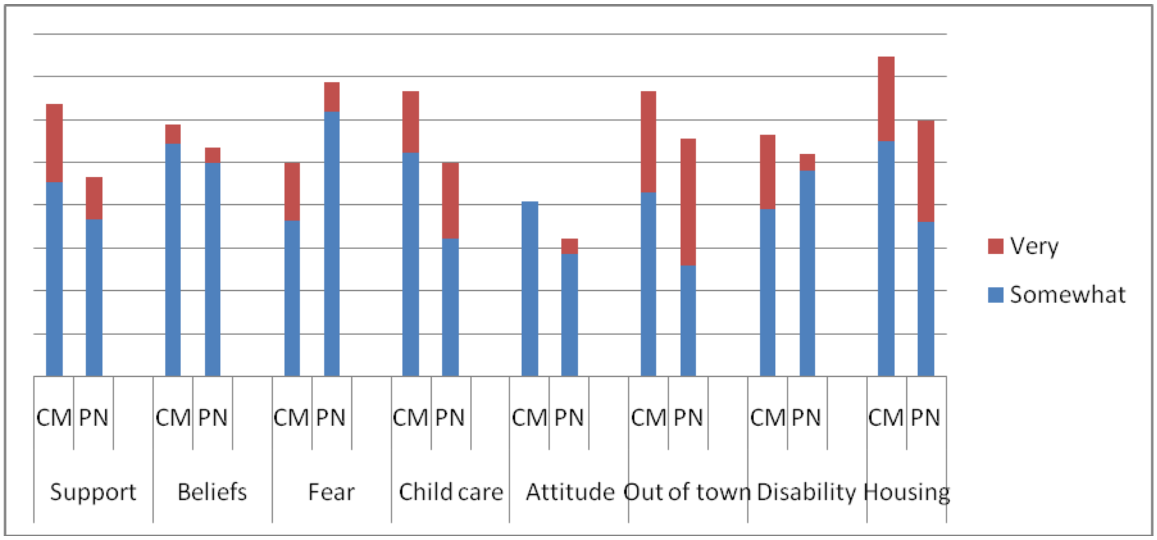
But another case manager found that many patients were able to handle news bout abnormal test results without excessive fear.

> I'm sure they're apprehensive to get a call like something abnormal and they need to follow up but for the most part I think, I think they're okay. We get a few that become anxious so we try to help them through that but most of them are fine. They roll with the punches.

The psychosocial needs that were rated as most difficult to meet were not consistent with those that were most common (Exhibit 9). Needs related to patients being out of town, disabled, and having housing problems were rated as most difficult to meet, even though not common. Needs for child care and those stemming from fear were also rated as quite difficult to meet, although they were not among the most common needs. Needs for social support and beliefs about tests and treatment were also rated as difficult to meet. Most needs were rated as more difficult to meet by case managers than by patient navigators.

Exhibit 9

Difficulty Meeting Patient Psychosocial Needs



Patient navigators were sometimes able to provide escorts to patients who lacked any other source of social support. A patient navigator gave a compelling example.

> We have patients that are completely alone. … before we had the benefits of providing an escort we had a patient that we waited, we waited for a while and then thank God we got this benefit of providing the escort, but he said, 'my neighbors don't like me. I'm an overweight person. I don't have a sister-in-law because I never had brothers and sisters, my parents died very young, my ex-girlfriend left me.' So, we do come up with this sometimes and you need to listen and be empathetic. If you don't have empathy, you know, I mean you need to put yourself in the person's shoes and you - because you really have this compassion and empathy. Not feeling sorry! That's the difference but putting yourself in this person's shoes and you will understand where they're coming from

> and you navigate with the person until the end and you make sure that they know that. And that person had it done.

A case manager also provided a compelling example of how social support could be provided.

> when the patient comes in for the provider and/or for me never brings the blood sugar log, never brings medicine, doesn't take medicine, takes it sometimes, can't really get information from the patient that's accurate and the daughter who is the PCA is not providing the care that she needs to, to her mother so after a conversation with the provider I decided that we needed to have additional support for the patient at home so what I did was talk to one of our advocates. … you know, it's going to take more than one person, more than one or two people to help this patient be health and stay healthy. So, we took the advocate, we talked to the advocate, the advocate called the … the insurance company … so between them going into the home to make an assessment to see how we can get this patient to take her medication so she doesn't come in with her blood pressures super high and also to help her daughter to understand what her role and responsibilities are so when she comes in she has all her medication, her blood sugar values are different, that she is compliant with her appointments and what we have begun to see is that her blood

> sugar is better, she brings in her logs and she brings in her medications. So, and it was done in a way that is in a supportive manner, you know, because she has, you know, and it's done in her language so that was the other piece so when you have, you know, culturally responsive people going in from that end that can go, you know, this is what's going on there … it makes such a huge difference.

Some patient navigators' comments illustrate the difficulties that can be caused by cultural beliefs, as well as the value of staff who from similar cultural backgrounds.

> most of our patients have different cultures different backgrounds, different beliefs so a lot of them don't – could hesitate to have a certain appointment done due to cultural problems or cultural beliefs … if there is a whole background and a whole family supporting their decision based on their cultural problems or beliefs so I think that's the toughest one.
>
> the Asian people their culture is very, you know closed up and they are not really, they have really strong beliefs … his second colonoscopy …he was just hesitant to do it because of their cultural background and it was unacceptable and it was very hard to deal with; very, very complicated to speak with him about the medical needs of the procedure and that totally conflicts with their religion or with their background so it's a very tough situation and we are very fortunate to have Asian workers here. …We have

> Vietnamese and Thai translators that are from that country they are usually very good at going around you know with the patient and just like really manage to explain them and convince them of the, really the necessity of it and the need of getting it over with so it's – worked out fine but it's very, it's a very tough situation.

The impact of cultural beliefs could compound difficulties due to language.

> I speak Haitian Creole, so I called her and talked to her. But sometimes I feel too, the patient needs somebody that, in the culture, …I know some of my patients from my culture, they will not speak in front of a man. If you're talking to a man [even as an interpreter], certain questions, they will not ask.

A patient navigator working with Brazilian patients identified special problems due to their prior experiences.

> especially with the Brazilian community, because we don't work in the same area as them, it's hard to help them and they have like sometimes a hard time to get a transportation to go to the appointments and they work very hard so to me that part I don't like because we book the appointments so many times, three or four times and they never keep the appointments, there are some patients that they don't feel that they need go to the physical, that's not important to them so it's very hard we have to do like brain wash with them and sometimes it's very hard because we have to keep calling them and keep doing education to them to do it. …it's

> not the training, it's the Brazilian community, they have a different feeling about that, because in Brazil you don't usually do the screening, you just go to the doctor when you have some pain, when you have some problems and to educate them that they have to do the screening to prevent is very hard. 'why do I have to do this test?' So sometimes it's hard to get them, especially with mammogram, colonoscopy, for physical and pap is easy, and blood work, but the other test the other screen it's hard sometimes.

Another patient navigator pointed to problems with Hispanics' health behaviors for similar reasons.

> I am Hispanic …. Americans are always on top of their appointments even though we call them but they always say "oh yeah I did know" and it's weird because you have to follow Hispanics and you have to be on top of them because they will say, "OH did I ask for this appointment?" or "OH I didn't come because nobody called me" so it's okay. You feel, like you said, somehow responsible that I have to provide a follow up and be more careful with this patient or this other patient because I really don't, but you do see their effort that they want to come. A lot of them feel guilty when they haven't shown up for appointments because they didn't remember or they didn't receive their messages on time or whatever, but generally I see they are grateful. One thing I love, is that Hispanics are very grateful for the follow-

> up we give them, they come and they show it with words, it's very rare to see an angry Hispanic, they feel like "wow, they are giving me a service and I have to be very grateful because they are –" Typically they come especially Hispanics, they thank you and they say, "OH, thank you" or they come to me and say "oh you know what I didn't make it to my appointment and it's too – " We somehow, maybe it sounds flattering but we are helping educate them, we are educating them, "Look you are resp0onsible for your insurance, because if you get a letter you are responsible for your appointments" we educate them, they come. SO I would say a typical one, comes to their appointments, they make an effort to come to their appointments, they worry about, to see what their follow-up should be, that would be me and I think they're learning, we are learning form them and I think they are getting used to this lifestyle in the United States, different form the American, the American comes to their – so the typical American, born here in North America and raised here, comes here for their appointments and you don't have to call them all the time.

Cultural issues did not necessarily lead to problems in service provision, but simply to different orientations that the patient navigators had to understand.

> they want you to help them with a million things that aren't in your hands and they tell you their story, but that's a very cultural thing,

> you come to handle it, they tell you about their family and they want to tell you all of their stories but it's not that frequent.

Case managers reported the same types of experience.

> her primary doctor was away. …they were putting her in with a resident who was a male doctor and when she didn't show for the appointment… …so I work with educating the patients on becoming stronger advocates for themselves, … she wants a female doctor and that's probably why she didn't go to that other last appointment because it was a male doctor. …When you go through treatment like that you really need to be connected with your physician as well as your oncologist, you know, you need to create a team of doctors and you're the center of the team. The patient is the center of that team. .

Patient navigators provided some case managers with essential support in delivering health information to patients from other cultures.

> I think all the support of the navigators, is really helpful. It's … not just a, an issue of translators. It's, you know, how to explain to people from, Thailand or Haiti, what we're thinking about this. Why we think this is important and why we, you know, why we want them to consider, having a procedure or test for. Because, you know—I think that that's having people that understand that culture and that language is, is really critical to that.

Fear of results was a barrier to follow-up testing that some case managers were able to overcome through reassuring explanations and sympathetic attention to patients.

> She had a history of breast cancer. She had another mammogram where she had to go to get additional views. She was like in panic mode and so I called her up and said “how are you doing and she said “well I have to go back for more tests” and I said “I saw that, that’s why I am calling you, are you afraid?” and we just talked about how afraid she was and it ended up all being just a benign finding but tried to reassure her that you know sometimes needing the additional views means they need magnifying views cause what they had didn’t show what they were looking, the area they wanted to look at very closely and so explaining that to her but of course the last time she had magnifying views it ended up leading to a biopsy and treatment. And it’s just talking them through and talking about all the anxiety she had around it. I mean she still remains pretty anxious all the time, I mean every mammogram that there’s like this bomb waiting to go off and so that’s – I’ve been following her for two years now so she’s used to that fear, and she talks about and it’s great that she talks about it. It almost be kind of nice to have you know regular meetings and support groups

Fears could also simply reflect lack of knowledge, which case managers tried to provide.

> kind of asked her if she had any other questions but she really wasn’t sure what that meant. She said “the cells are abnormal that

> mean it could be cancer" and I said "well it means that something is there and that can be beginning changes, so under the microscope there are beginning changes we just want to watch it" simple language because when they get their little letters it has pretty complex language on their little letters: your results show some atypical changes, well atypical what does that mean to them.

One case manager added that knowledge would only be helpful if a patient was ready to use it as a basis for change.

> they don't understand metabolic syndrome … and it's really hard to explain to them cause they're kind of like, "well, what do I do to change it?" and then you try to explain "well if you can do a diet, nutrition, exercise, all things hard to start" So it all that readiness for change, so I try to meet them where they are at, having that kind of conversation you decide if they're ready for change and if they are, then we can move along if not we can say "well this is what I can offer you."

One patient navigator explained how she told stories to explain the process.

> Like story telling them how people before them went through the process. It helps them reassure that the whole procedure will not be as complicated as they think if they follow the whole process step by step but it takes time for them to process it too.

Fears were often related to immigration status. A patient navigator explained:

a free screening event here annually and had her blood pressure checked and it was, like, 210, 220 over 110 or something ridiculously high and … somebody who saw that later was, like, oh my God, like, … so they wanted her to come back in and have her blood pressure checked again and to have her-- Somebody must have been going over the data later, saw it, and was, like, well, we need to do something about that (laughs). So they ended up reaching the patient, but she was uninsured, and, you know, not on any meds or anything like that. So, she was referred to us to get set up with primary care. …so I had worked with her and got her on health insurance, and we got her in to see primary care and she's been going and she's on medications and things like that, and I guess she called me, last, eh, two weeks ago and she said she got something in the mail from Mass Health and, she didn't know what it meant. She was really confused. .. she called me and she was, like, what's going on? And I was like, just come here and, like, we'll work it out. Just bring it in and, like, meet with me and we'll see what it is. … so I took her to patient financial services, which is like our health insurance office here, and basically they went through and totally reviewed it for her. … she got really nervous and thought it was, like, something about immigration. Actually, she said, I thought the white man was coming to get me. She's undocumented.

> So, she, like, freaked out--And never went back to the health center. … So, it's just satisfying to me that she'd called me up right away and said, like, what do I do? And that she wasn't scared again and that she came in and we took her in and she had it done and, like, it was fine. So, now, you know, I told her, like, you're going to get this every year and it's fine and this is what you have to do. You just come here, but you have to do it right away 'cause then, of course, there are other people who are like, oh yeah, I got that form in the mail, like, a month ago, but I forgot about it and then their Mass Health gets cut off. So I'm always like, oh, why didn't you tell me? Like, I could've helped you with it and now it's like a pain to go back and redo it and then their coverage gets, messed up. So, to me, that was satisfying 'cause I was like, okay, I really appreciate when people actually call me when they have an issue because then, or, you know, and people who I haven't worked with very extensively, but I guess they still remember me, call me up when they have a breast lump or something like that.

Case managers described the same type of problems due to immigration status:

> If I'm in this country illegally and I'm working in a restaurant and maybe my one meal a day is what they're gonna give me at the restaurant I'm not about to say, 'I need three ounces of lean chicken and I need brown rice' or if I'm not working I'm not getting paid so if I feel okay why should I be going to have a

> screening colonoscopy or have my mammogram or see the doctor if I’m not sick? And I don’t have transportation to get there anyway and I can’t afford the gas or we’re being targeted or labeled and, you know, we go to Price Chopper in a car and the police are waiting there to see the car pull up and they’re snaggin’ us all and we’re being deported.
>
> a lot of them aren’t legal …, so that requires a lot of working with social work … – it’s very challenging and a lot of people are really afraid to tell anybody that they are not legal so like a lot of people for example you’ll call – by the time you get down to it, you will call and say “well, geez why haven’t you taken your medications for a month” and they’re even afraid to tell you that and they don’t want to pursue applying for anything else so they’ll try to pay for them on their own and then they’re not eating cause they’re trying to pay for their medication so yeah so that’s a big hurdle.

However, as one case manager recalled, some patients eventually overcame barriers created by immigrant status and made a successful transition to the labor force.

> We see a lot of people who are newly here but we have a lot of people in the Brazilian community that have been here for years and years and they go on to… you know, they’re able to get insurance and have jobs and they may start off when we first know them as people who don’t have a Social Security Number, you know, I’ve seen a lot of people make that change.

The attitudes of patients who were inclined to reject help also created a barrier to care. As one patient navigator explained,

> you know when they tell you “I’ll call you” they never do. … we have many, many patients that come in and they want nothing to do “oh, no I am very good at it, I take care of this, this and that.

One patient navigator provided a compelling example of how she managed to overcome this barrier:

> this patient comes in once a year, so of course the patient is always overdue for everything … they don’t return our calls or they make an appointment and then they cancel, … I was looking at this chart and the patient had called that day and was going to come in the following day for a sick visit ‘cause the patient was not feeling well so I said okay, that’s nice, I will go downstairs and see if they can catch a patient for the eye appointment like right after … and when the patient get here I will see if mammo has a spot for the patient, they did, and we got all the labs.

Distrust of providers could also be a problem for patient navigators.

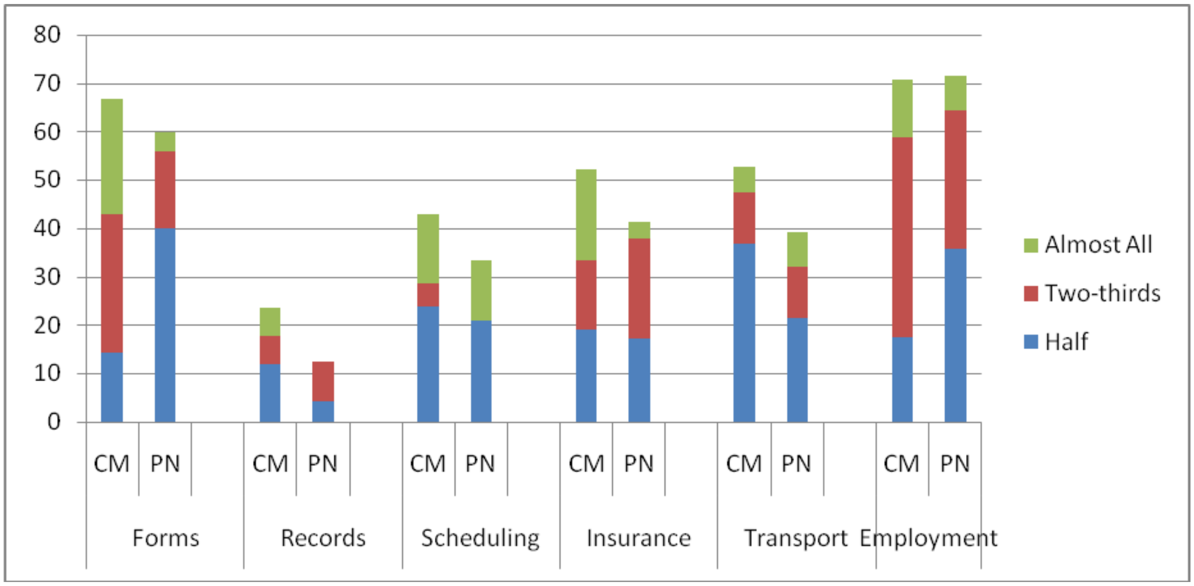
> you can do whatever you can to be there at their appointments even accompany them at their appointments but if it’s something that is innate in them, it’s kind of hard to change that thought and let them recognize that the providers is here to help them and not just to take their blood test or whatever

Practical Needs

Both case managers and patient navigators identified unmet practical needs among many of their patients (Exhibit 10). Employment needs are most common—70% of both patient navigators and case managers reported them among at least half of their patients—followed by "completing forms" (about 60%), transportation problems (40-50%), insurance issues (40-50%), and scheduling problems (30-40%). Problems with obtaining medical records were much less common (10-20%).

Exhibit 10

Prevalence of Patient Practical Needs



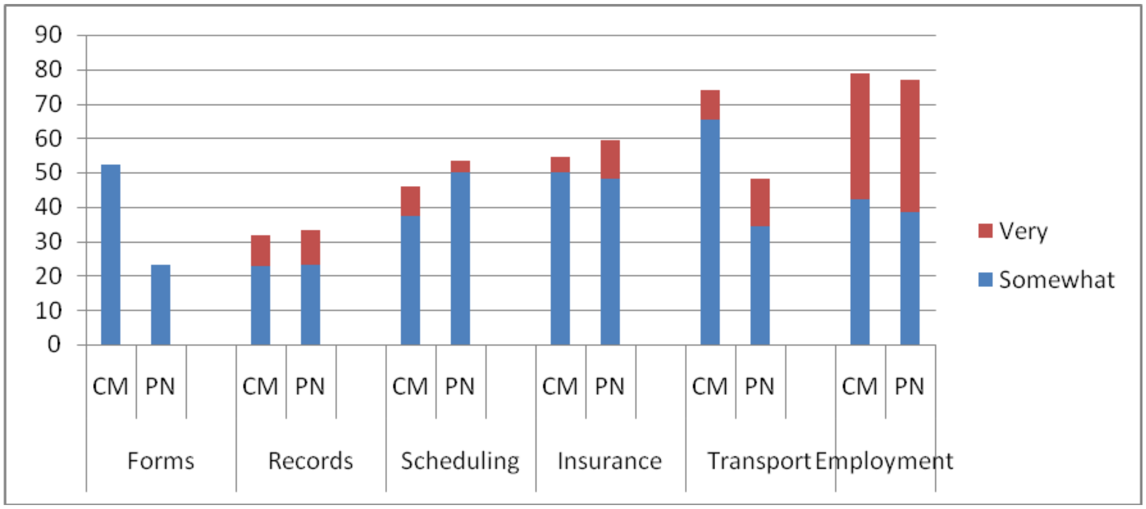
Of course, patient navigators explained, the primary barrier related to employment and some other barriers was low income.

> she was actually getting her light shut off, two week ago, because she didn't pay, but she is so sick and she only gets seven hundred and like eight dollars a month to live off of and obviously after rent and food there is nothing.

Both case managers and patient navigators rated employment problems as being the most difficult practical patient needs to meet—somewhat or very difficult or more than two-thirds of their patients (Exhibit 11).

Exhibit 11

Difficulty Meeting Patient Practical Needs



Patient navigators provided examples of problems that they were not able to solve stemming from lack of a job as well as from the constraints of a job.

> don’t have a job, they don’t have food, it’s hard to manage the patient that have diabetes, and you ask “Okay did you eat fruits or vegetables” and they say “I don’t know if ii have food today” you know and they say “I just have rice, just to have beans” you know how I can educate this person, they feel so hungry? … sometimes they come here just for enjoy the group or enjoy the visit because they need to talk, just talk so this is, sometimes we feel like I cannot do nothing. I try to research, I try some two-dollar bag for patient, I try some soup from the church, I try dresses for this

> people, I try places for stay, I try so many things but sometimes we cannot find.
>
> Another thing is fear for their work, sometimes, you know this patient needs an appointment an it is important, for example a diabetic patient and he says "I can't come to this appointment with the nutritionist because my boss won't let me, he won't allow me to go, I can't because they won't allow me, I only have that day free" And I say you have a month talk to him and ask for a change "No, I can't" these are situations that are real barriers, fear barriers because they don't know they have rights for their health they are allowed to ask for a day off or ask to start later so they can come and work later. Those are situation that…but at the same time we try to help them, telling them you have rights, you can ask for this authorization in advance, but it is a barrier, because I have felt frustrated when I see that a patient needs an appointment, a patient, a woman she is three years overdue for her Pap, she hasn't had a mammogram, I know it's important for her to get it done and she tells me, "I can't ask for permission."

Illness could itself be the source of employment problems, and, again, sometimes patient navigators found there was little they could do.

> If they have cancer and they're going through treatments they usually have to take a leave of absence and they're worried about their jobs. Some of them lose their jobs…. We had one lady that

> her husband lost their job, she'd been a home maker, she came in and she'd been living on four tortillas a day, luckily we had some funds here and I gave her information on a food pantry.

Oftentimes, however, staff found ways to deal with these practical problems that affected the ability of patients to receive health care. A case manager gave an example:

> For health issues we work with their physician, to see what the best plan of treatment would be. For the practical, we give bus passes, cab vouchers, umm we refer, well we take them over to the HBA agent for the insurance issues, and they're wonderful here. They sit with them and they go over everything, they've signed people up, they spend hours unraveling messes. Scheduling? We've walked out with patients, I walk them out to book the appointment, we overbook, we come in early or stay late. I don't know about the records, we send them up here. The forms, we help them fill out, the navigator helps them fill out the forms and the employment issues I can't say but we send them upstairs to the psychologist for the depression and social service works with them as well if they need help with their parents like Meals on Wheels, Elder Care Services, Food Stamps, vouchers, things like that.

Patient navigators also found ways to overcome income-based problems.

> she was actually getting her light shut off, two week ago, because she didn't pay, but she is so sick and she only gets seven hundred and like eight dollars a month to live off of and obviously after

> rent and food there is nothing, so I had actually worked with her to make sure she didn't get her lights shut off and had the doctors fill out a medical waiver, so now they can't shut her lights of for six months.
>
> He called back and he couldn't get a specific medication a patch that was too expensive and I guess it cost a fortune, …so she went above and beyond and called the social worker to see if he could help him with that and he couldn't so she went to another doctor to see if they could switch the med and they ended up switching it to clonidine by mouth which he could buy at walmart for three dollars so …worked and really followed through on that.
>
> [Although in this case the patient did not pick up the medication and ended up back in the hospital.]

Resolving transportation needs was often a key to successful service provision, although these needs were rated as very difficult for more patients by case managers than by patient navigators.

> we tried to get this lady to have her colonoscopy done she would always miss the appointment. She probably missed five appointments. The specialist wouldn't book anymore appointments for her because she had no-showed so many times so obviously, you know, he's losing money by giving her appointments over and over again so I did reach out to her to see what was going on. I figured out what her issues were. Her issues were transportation so

> we hooked her up.… It's Mass Health offers that service, it's transportation, to patients that need it. Obviously they need to meet criteria, which she did. So, we got her hooked up with that and I found a specialist that would see her and kind of counseled her, you really need to go and she got it and she appreciated it.

Transportation problems were rated by case managers as almost as important a barrier to health care as employment issues.

> there's never enough money…. The big one here is transportation, … it's a huge deal. It's an enormous friggin' deal …so if you have Mass Health you can apply for a public transportation voucher. Well, if that doesn't get approved or if you don't have Mass Health you're screwed! … it's trying to get support for some maybe out of the box responses to things. It's like the programs are gonna end, okay! … The pace here is terrible (the word terrible is whispered) for everybody so people are fried. It's like hard to rally.
>
> he called the clinic saying that he didn't have money to make it, he was coming from Lynn, so that he didn't have money to come from Lynn to the Cambridge Hospital and he also didn't have money to pay the copays for the medication.

Lack of transportation could be a major health care barrier in some rural areas, but a case manager explained how she overcame it:

> I use American Cancer to link them up with transportation, no chemotherapy for cancer is done in South County, you have to go

> to Pittsfield, twenty-two miles north; forty-four miles if you're coming like from town. If you're just above the Connecticut border it can be a haul, gas is four bucks a gallon, you know, if you're having a six hour chemo treatment it's an hour up and down; How are you getting there? How are you getting back? So, I use American Cancer; I have volunteers that will help with transportation

Insurance and scheduling were also rated as very or somewhat difficult by over half of patients of both case managers and patient navigators. Needs related to forms and records were rated less often as difficult. Patient navigators explained the types of problems that arose with patients about funding.

> The major challenges are funding, … there are still some patients that are floating out there that can't have a test because of insurance issues … not all can afford insurance and its just awful that these patients they can't afford their medication or whatever. the patients that are eligible for the insurance we get enrolled in insurance right away but the problem is the ones that are not eligible for insurance who are on health safety net and that all they'll ever get, that where our biggest problem is, finding providers or offices that are able to do pro-bono or will take health safety net that's very, very hard.

Case managers had similar experiences.

> Brazilian population the jobs is very difficult because they tend to work a lot and a lot of them don't get health care through their employers so most of them are their own health safety net, so that tends to be challenging sometimes when they need certain things that aren't covered durable medical equipment like oxygen tanks is a problem I've had with a few patients referred to me cause they need an oxygen tank and it just doesn't cover that so, it's challenging

Sometimes the problem was due to misunderstanding.

> apparently they thought they had no insurance, so I kind of checked on that, they in fact did have an active insurance. … I sent a message to the provider to refill these meds urgently, it got refilled within the same day for the patient, that was my priority so umm and the patient was very grateful about that, … the provider didn't have any openings 'till June, but we needed to see this patient way before that, because his diabetes hasn't been so well controlled so really working to accommodate their needs so I contacted the provider and I was asking "Can you have this patient come in? Can we overbook? This patient really needs to be seen this was what was going on" the provider replied promptly and we were able to get the patient in next week. … so I kind of took care of all of that. You know what she was very, very grateful and appreciative of that so yeah…

Among these practical problems, employment problems most often made service provision difficult for patient navigators and case managers. According to one patient navigator,

> A typical patient, is always on the run, always rushing, that's typical, rushing, …they have long hours, especially Brazilian. but is very grateful for the service we provide them, always very grateful, most cases give us very good feedback …. those who right now don't have a job, they have all the time in the world.

Others described employment problems that were connected to immigration status:

> A typical patient… immigrant, who works two jobs, who has a family who finds it very difficult to come to their appointments, when they come to their appointments they need to be seen promptly because they have to go back to work because their supervisor won't understand that you know, Very busy, busy life, and a lot of the patients too come and go, come and go so they go back to their country, they come back so it's very difficult because you know specially if they have you know a chronic illness or if they have abnormal findings.
>
> a typical patient here, so I'd say for the most part is an immigrant that's a typical patient here immigrant, who works two jobs, who has a family who finds it very difficult to come to their appointments, when they come to their appointments they need to be seen promptly because they have to go back to work because their supervisor won't understand that you know, they are here and

> they don’t want to lose pay or lose their job… Very busy, busy life, and a lot of the patients too come and go, come and go so they go back to their country, they come back so it’s very difficult because you know specially if they have you know a chronic illness or if they have abnormal findings where we are trying to get this patient in and then they are out of the country but we don’t know that cause they sometimes don’t let us know and then keeping track of them and when they come back, making sure they come back, it‘s just kind of crazy…but that’s the typical patient: immigrant, so…
>
> a lot of them are immigrants, a lot of them have no sick time they have not the greatest job, a lot of them self-employed a lot of them work under the table and they do not have time to come in here repeatedly, they like the phone call contact and they don’t really want to come in and see somebody, even one, even when patients become diabetic and there is a list of things we want them to see, sometimes it’s just a lot and they can’t get the time off.

Problems with records were not rated as one of the least frequent and difficult barriers to care, but some comments highlighted the difficulties due to patients’ lack of recall of their own health history and the importance of good medical records.

> if they said “oh, I had a mammogram” I can see if they’ve had it in our hospital ‘cause we utilize our hospital for everything and we use their data base system and their EMR so we’ll see what they’ve

> had, but if it's internally I can just pull the chart or I can pull up the records on the computer but I am always looking at their charts because some people don't know they had a physical or they say "oh I had a physical" and I'll check and see actually that was a follow-up that you were here for and you know when was your last mammogram and "what's a mammogram?" you know or colonoscopy is a big one, they don't know if they had one…. like with the insurances especially they may not have a social security card, so then I have to get them to go to the social security administration to get one and you know come back with that so we can apply for insurance, so we are doing different things daily.

Communication Needs

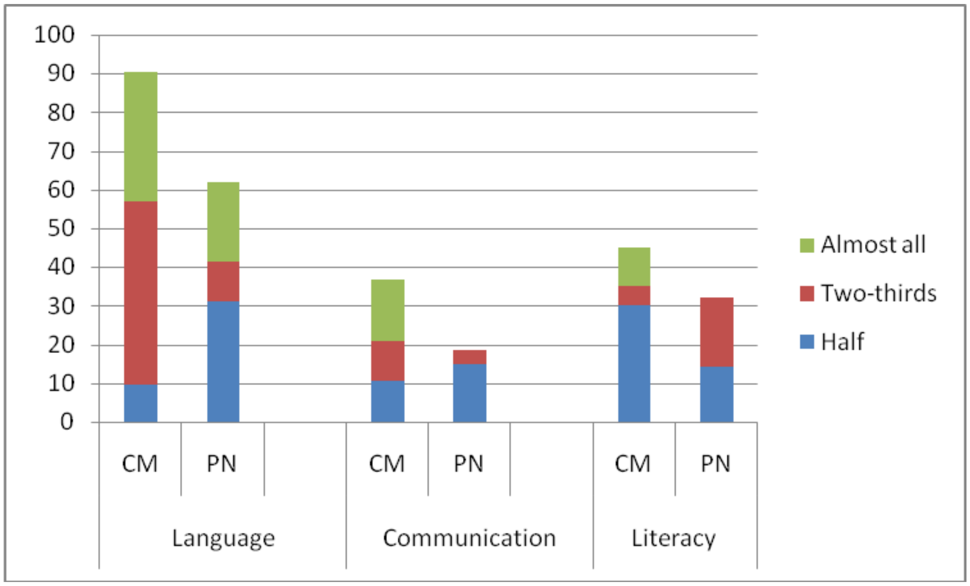
Among the three types of communication needs listed, language or interpreter needs were by far the most common (Exhibit 12). Ninety percent of the case managers reported that at least half of their patients had language or interpreter needs, and most of those reported this need for two-thirds or more of their patients. Language needs were also the most prevalent patient communication need reported by patient navigators, but they were still much less frequently encountered. Only 60% of the patient navigators reported that at least half of their patients had a language need. General needs involving communication and literacy were much less common, but in both cases case managers reported that their patients had more such needs than did patient navigators.

Phone interpreters were often used to communicate with patients who did not speak English or Spanish, but the arrangement created some problems.

> we are getting more and more providers and less and less speak in Portuguese so the interpreter's time is a premium and nurses don't get top priority doctors to. I use the phone interpreters all the time and sometimes it's a lot to do, you know have people here and have some women talking to me, who's got a cough, I got the phone interpreter she can't hear she is on top of the phone, she is coughing in my face….

Exhibit 12

Prevalence of Patient Communication Needs



Rating of the difficulty of meeting communication needs did not follow the same pattern as rating of the prevalence of these needs (Exhibit 13). Literacy was rated as the most difficult communication need to meet, particularly by case managers—almost all of whom rated it as very or somewhat difficult. Both language and communication needs were rated as not often "very difficult" to meet.

As one case manager explained, literacy issues increased the service workload.

> if there is a literacy issue ,,, they need a little extra help or teaching, … but to keep her on her medications and keep her healthy she needs to take her medications at the right time and because she can't read she doesn't know when to do it so if I don't keep her on the clock system….

Lack of medical literacy was itself a problem, as a patient navigator explained.

> some of them have very low, very, very low understanding, they don't know very little about, they know very little about medicine or certain procedures. Some of them don't understand if you tell them "you're diabetic" or if you say the doctor said you're diabetic, they have no idea what that means. Very low comprehension but then there are other patients that are very savvy and very professional.

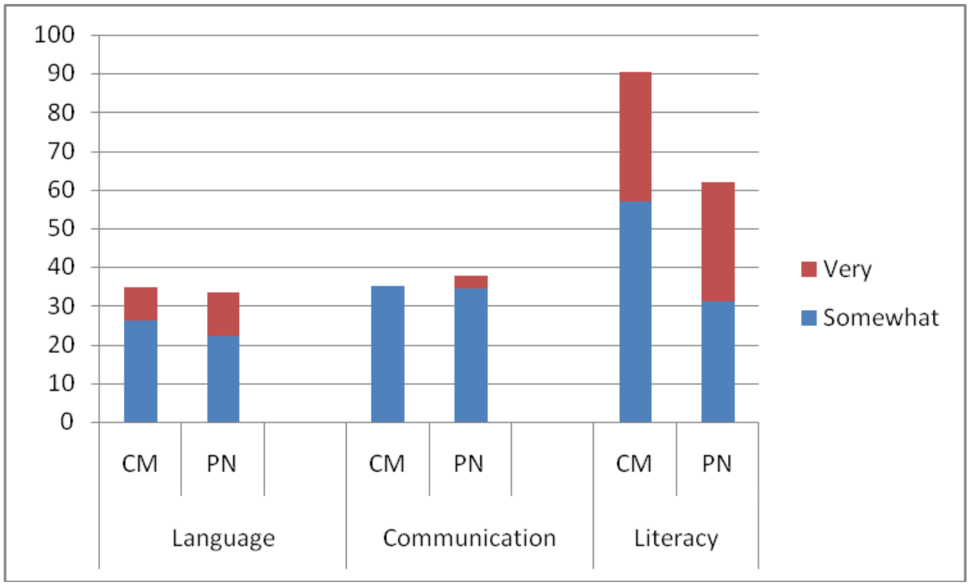
However, literacy problems could be overcome by creative case managers.

> I have one that brings in all of her medications and we put dots on it so she – and then she has a color chart of when she is supposed to take it. Things like that, things were they need a little extra help or teaching, I mean that's not something that is covered in the contract that I am labeling her medications but to keep her on her medications and keep her healthy she needs to take her medications at the right time and because she can't read she doesn't know when to do it so if I don't keep her on the clock system - and then I wrote it all out for the physician so if the

> physician sees her and she talks about the purple dot bottle or the red dot bottle (laughs) instead of the names.

Exhibit 13

Difficulty Meeting Communication Needs



Language problems could themselves make service provision “really difficult and really frustrating.” A patient navigator and a case manager explained why:

> I don't speak Spanish. So, there has been, maybe about one to two patients within, like, the last month. I just couldn't do much to assist them because I don't any Spanish. Like, I have very limited materials, very limited anything that I can actually assist 'em and give them. So, it's like, the communication part is a big issue for me.
>
> we remind them to keep checking with the waiting process some people are good with keeping up but if theres’ a language barrier they always need somebody there with them all the time. It’s just

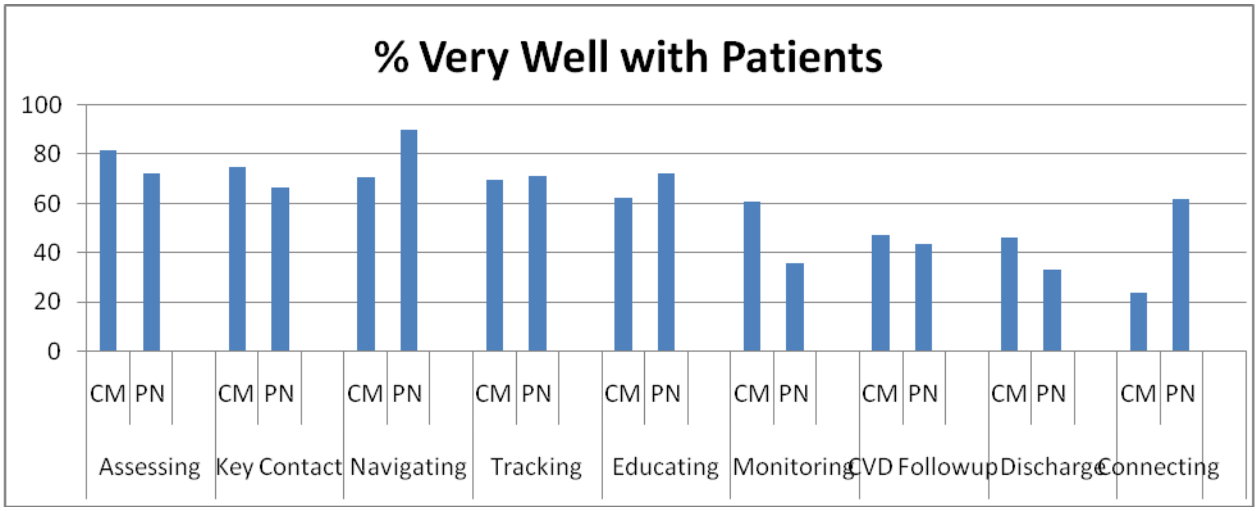
> time consuming and if it's an emergency type stuff it's hard if they don't give you time in advance they just call you when they need the help right away. … If they speak English it's easier, if they don't I always go out of my way to help them with the process.

Evaluation of Program Activities

A number of essential service activities were rated as carried out "very well" by between 60 and 80 percent of both case managers and patient navigators: assessing patient needs, providing patients with a key contact person, navigating patients (rated particularly highly by patient navigators), tracking test results and educating patients (Exhibit 14). Service activities that were not rated so highly were arranging for follow-up CVD screening, arranging for discharge, monitoring progress (given a low rating by patient navigators), and finding/connecting with patients (given a low rating by case managers).

Exhibit 14

Staff Ratings of Patient Services



A patient navigator explained why educating patients about managing their health was so important.

> we have a lot of patients that have … alcohol and things like that so it's a community with a low income so they need a lot of help. Typically they don't know a lot about a themselves and how to manage their health ….i would sometimes enroll them in the program and also go over and give more information about health maintenance, teaching them into how to become a more – empowering for they become more knowledgeable about their own situation.

Patient navigators who already knew potential patients, often because of prior positions at the health center, found it easier to enroll patients in the program than did those who did not have such prior relationships.

> Some of my patients, most of them they know me here, I didn't have a hard time enrolling them into the program, because …I'm always here.
>
> It's all about the relationship, they call us and say I need this I need that, and we help them so they know us… I did a lot of outreach. So everybody knows me, some people come here they go to the front and they ask for me.

One patient navigator had become known in her community because of appearances on a health care program on TV.

> Good interaction when we see each other face to face, some of them do know who I am because we do the tv show so when I call

> them they always ask am I on that tv program so they are very open because they already know who I am in the community.

Doctors and patient navigators worked together to connect with patients in some centers.

> even the doctor with new patients, the doctor automatically calls us and helps us, “this patient has certain priority or don’t worry about this one’s physical yet because it’s more important to prioritize that other case, it depends on the patient’s health,… because patients we already have, we know their situation and we give the follow-up but with the new patient we don’t know their health so we have to immediately get in touch with the patient, and then the doctor knows the patient is coming, I go and tell them there is a new patient coming, I would like for you too and so on. There is constant communication between the doctors, we go to the patient and we tell them after the doctor sees you we need to see you, bla, bla, bla and we explain.

Patients could be difficult to connect with for a variety of reasons. Time was often a problem.

> the time factor, reaching patients at home, getting them to commit to taking time out for their care although I’ve been surprised that a lot of people are really into it, like I said that they’re actually happy that like someone is doing that for them

Some of the connection difficulties differed by gender.

> we started with male and female, it was very, very hard to enroll male, I think in the first year we only had about fifteen because it was very hard to convince the men that they do get sick and they should come in and do preventive medicine, you know high blood pressure, there is another thing they need just because they don't have a symptom they don't think they're sick, so it was very hard to draw them in. … after a year … we were only doing women so in the beginning we said "Oh great women are going to work a lot better because you know, they are mothers, they are wives, they're sisters and girlfriends, they have children, they are the nurturing type who need to be healthy in order to take care of other people". So it was great in the beginning we were able to enroll a lot of women but then all of a sudden you get to a certain age, I don't know what it is or what the reasoning is behind it; it was hard to get the women to come in, there is a lot of women that are working also and they don't think that need to come to the doctors to do their prevention.

Many patient navigators had found that patients were most likely to enroll in the program if they were approached in person, at the time of a scheduled visit for a health problem.

> Sometimes we go down to the health center, to do some registrations there directly when we want to promote the program, because of low numbers in registration and some times, what are they called, the front office persons they haven't been on the

lookout for women 40 to 64 who need screenings, so we do like a promotion or something, in other words we offer them services so they can go there to the health center and when they get there they are sitting in the waiting list – in the waiting room. We ask them if they want to be part of the program, and if they are interested in the support we can provide, we will help them with everything in their medical care, disease risk reduction, we explain what the program is about and many times we get – their signature for the consent and then from there we enroll them so…but that's something that happens every week

What I used to do is I would kind of call them the day before and give them the heads up but it wasn't really effective and a lot of people were like "what program?" and " What are you talking about?" or "Do I have to do this?" and "Are you selling me something?" And I am like "no, no I work at your doctor's office" So I started finding it was better to get them when they are actually at the health center, the same day and I initially what I did was I in our practice management system I was able to put a little alert, like send this person to H or this person is not enroll please have her see me, but then I found it's too hard with front desk they are busy, you know they may see it but not even think about it. So what I did was is starting – I just started coming in and okay Mary is here you know at nine and Mary can I talk to you for five minutes and I just initiate a conversation with her “This is what we can offer to you, you’re not currently enrolled, this is what we can give you for services, you know have you had these services, do you know what these services are” and then just go from there and then face to face is pretty much primarily how we try to do everything, because our patients may be here today and gone tomorrow, so they are really hard to get or they have cell phones and their minutes are you know costing them money and they can utilize them. So get everything upfront, so actually I enroll them, then I do the paperwork involved with that, then I do the commuter paper work involved with that, get all their screenings booked and then I start creating charts for them, if they are new patients, if they are already existing patients I find their medical charts in the health center and we’ve created a system now where we actually put a tab in their charts and we label the outside of their charts with a green sticker so they know that they are enrolled, so that way it alerts the physician, especially if there is a screening question, or a billing question can we order something, they know they can come seek me out. It also tells the physician they are linked with me so if there is any other services they need they can come back to me and then that way if they are not enrolled we know that’s a potential person we could potentially

> enroll later, so then after that's done for the day then I start looking for the next day.
>
> I try to have the first conversation by phone and I try to bring the patient to the clinic because I don't know if this patient is comfortable at the home, or some patients is uncomfortable on the phone so I prefer the patient to come in the clinic I try to bring them here, just to give them brief things of what I am doing here, what's my position here at the clinic, how I am working and so I start the conversation. Generally they come here to me because they feel more comfortable and they don't know who is closed in at home and we this hospital, we work very, very discrete on the confidentially, patient confidentially, so I love when the patients come here, because it's just me and the patients and they can tell me everything, and all this problem that they have…they feel secure, how's it going with his family, all these procedures, so I prefer one by one and but if they don't have time if they feel they are very comfortable that's okay I keep going on the phone and offer the services and offer my phone and say whatever they need to call me and so they call back

Once patients were enrolled in the program, the assessment process was often comprehensive, focused on health behaviors as well as on health status.

> we kind of get to know the patient, interview them, spend some time trying to figure out where they're at in terms of self-management goals, how they're thinking about their own illness and just explaining who we are and what our role is in getting them to take care of themselves … you partner with them, it's partnering with them to help them to be more responsible for their own healthcare. Some are extremely complicated because they have co-morbid conditions and so those are the harder ones and every patient isn't the same. Every patient doesn't sit at the visit and say, 'oh yes, okay, this is what I'm going to take care of tomorrow', it's not that way at all. Change is very, very difficult for patients, for everybody! …You have some that aren't so sick and there are some that are at a place where they're referred to prevent those complications with chronic illnesses and there are ones that are already there and you just really work very hard, frequently to try to get them to, from getting sicker actually.

Limiting most patient contact to phone calls seemed to some case managers to create problems.

> initially I thought I was supposed to be meeting with patients in person and I think that would be a more effective way to provide the services but given the amount of patients we have enrolled and the way the program was established form the beginning everything was supposed to be done over the phone which is very

> – not effective, I don't think. …I think in order to be an effective case manager I think you have to establish some kind of rapport with the patients …, it's very hard to call somebody because they've had you know, we need to talk about your hypertension or your diabetes and you know most people are on cell phones now you call they are at work or they're driving. … You know so I am just calling to remind you that you have an appointment tomorrow, but I need to talk to you about you know your diabetes is not something you want to do over the phone …so then I have to explain who I am and what my position is and why I am calling them in order to then move to my plan as a case manager and you can't do that over the phone with somebody you've never met.
> I think that we should at least try to provide an opportunity to come in and meet with the case manager because there is a lot more things going on as to why someone may not be managing their health as they should be or as to why they are not making it to appointment or they you know…a lot of those things can be external factors: unemployment, family problems, depression, you know and I think that calling people on the phone, cleaning a chart review is not the most effective way to do it.

Many staff rated follow-up as less successful than other program activities.

> you make the appointment you make a plan with the patient and then they don't show up, then I try to back track you know to find

> out what happened and I can’t reach them, and I get really frustrated. … it’s very, very hard when they are working two and three jobs and then their addresses change so often, their phone numbers change so often that’s the biggest burden I’ve seen at least is reaching them.
>
> Our population changes constantly, they change phone numbers, they move, they move to New York and like I say you have to wait until someone tells you after you call five times or even when you send a letter then the letter never comes back because their relative has taken the letters.
>
> they work very hard so to me that part I don’t like because we book the appointments so many times, three or four times and they never keep the appointments, there are some patients that they don’t feel that they need go to the physical, that’s not important to them so it’s very hard we have to do like brain wash with them and sometimes it’s very hard because we have to keep calling them and keep doing education to them to do it.

Nonetheless, persistence could pay off—even on the phone. “It takes a lot of effort to get patients to attend their appointments but we don’t give up.”

> I finally got her on the phone one day and we spoke about it and I told her how, like, her doctor wants her to have and even I want her to follow-up and would do whatever. I told her, I would do whatever it took just to get her there. I practically begged her. I

> said, please, just go, you know? She said, all right, I'm gonna go. Why do I have to do this? Da-da-da-da-da. So, it was like, I practically begged, but it was like I, I also, I think that she got that I kind a cared that I wanted her to follow-up. … it was like I was talking to one of my sisters. I'm like, please, you have to go. I came back and said, Dr. L, she went. She's like, oh my God! It was like a party between us two. But, you know, you get excited when a patient actually listens and wants to take care of themselves at some point. You do get excited…. I felt good because I never gave up on her. … I never give up on a patient, doesn't matter if it takes me a year or two. I just always have to—some patients will take a long time.

The personal relationships developed while patients were in the program sometimes continued for years to provide a source of staff satisfaction and patient health care advice.

> No, I am not very good at closing them out, I am really honest with you because they end up calling you anyhow, once they develop a relationship we kind of get to know the patient, interview them, spend some time trying to figure out where they're at in terms of self-management goals, how they're thinking about their own illness and just explaining who we are and what our role is in getting them to take care of themselves so it's, you know, a lot of education, umm and it's a lot of self-identification in helping patients to understand their illness and to establish

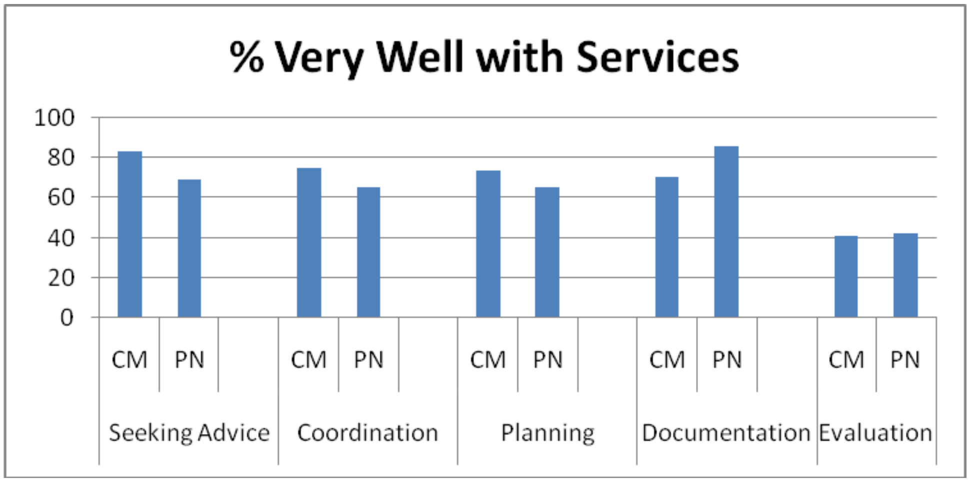
some of their own goals toward wellness and it also helps to give them… you partner with them, it's partnering with them to help them to be more responsible for their own healthcare. Some are extremely complicated because they have co-morbid conditions and so those are the harder ones and every patient isn't the same. Ever patient doesn't sit at the visit and say, 'oh yes, okay, this is what I'm going to take care of this tomorrow', it's not that way at all. Change is very very difficult for patients, for everybody! p …, they are still coming to me and they're still asking questions and it's because they are not comfortable telling people they can't read or write and they're not comfortable getting notices I mean we had a lady …she came to me because…because now she is on disability and she got Medicare, well she came to me and said "well I don't want Medicare I want to stay on Mass Health" and she didn't understand it at all and then we were trying to tell her it was a good thing but she also forgot to fill out a form for Mass Health so …she figures I saved her life and stuff, she still comes to me – she lives on six hundred a month so she came to me saying "well, I've made a decision, I've decided that I don't want to die of cancer, cause people that die of cancer, die a horrible long death but I am not going to be able to afford my heart medication so I am going not going to get that, cause if I die of a heart attack it'll be fast, so it was an awful dilemma for her but you know I am

> not going to turn her away when she comes to me with that kind of problem

Both patient navigators and case managers tended to rate program services as going very well, with at least two-thirds giving this high rating to how well the activities of seeking advice, coordinating services, planning services, and documenting services are being carried out (Exhibit 15). The one poorly rated activity was evaluating how well service is provided, with only 40% in both groups rating this activity as going "very well."

Exhibit 15

Staff Ratings of Program Services



A team approach to service delivery facilitated these different aspects of service provision. A case manager described how she served as the source of expertise for others at her center for managing oncology cases.

> I've done oncology for twenty years exclusively, … so the providers here know anything that looks, sounds, smells like cancer they're gonna come to me and I'm gonna help them manage that patient.

Others recounted the value of working as a team for dealing with complex health problems.

> I don't feel like I work like an island. That's why. Team… teamwork, really good teamwork. You can't work by yourself in this job, you have to have teamwork. There's too many aspects to the care, you know, like you could run into a transportation issue and a person in the health center if they deal with that are having a problem with their insurance- the Health Benefits might help you, I mean, there are so many avenues patients can go down and you have to help them. They have the barriers preventing them from getting the follow-up and no one person could do all of that.
>
> I have a strong support system, uh, within my job that makes me feel confident and in case I have questions or if something comes up, I can handle it. Even if I cannot handle it, I can get help.
>
> so I know all the doctors that usually contracted before so when you have to send the clients to them I have good connectors over there and at the hospital and at the clinics, so I have everything that I needed because I usually call them every single day, so many times a day.
>
> when we have the team meeting, we may bring a patient to the board that we are having difficulty having a certain test or may have a difficulty contacting for some reason but that they will know "oh, no, no that patient told me that patient was going out of

> state for three, to help her daughter with her new baby" or something like that, so the medical assistants are my really really close contact because they know the patients, they see the patients on a regular basis. They know who to call to get the patients, you know so they are my side, they are my link; they are my right hand man.
>
> we were like okay this is our mission this is what we are doing let's get it done, you know. And then if we had it one way that was more effective, we were all okay like how are you doing and we kind of start to try that. We always, we met in teams constantly so having the team meetings was really good cause if we had a problem with something we could get it out, or if we had a problem with each other we could hash it out in the meeting.

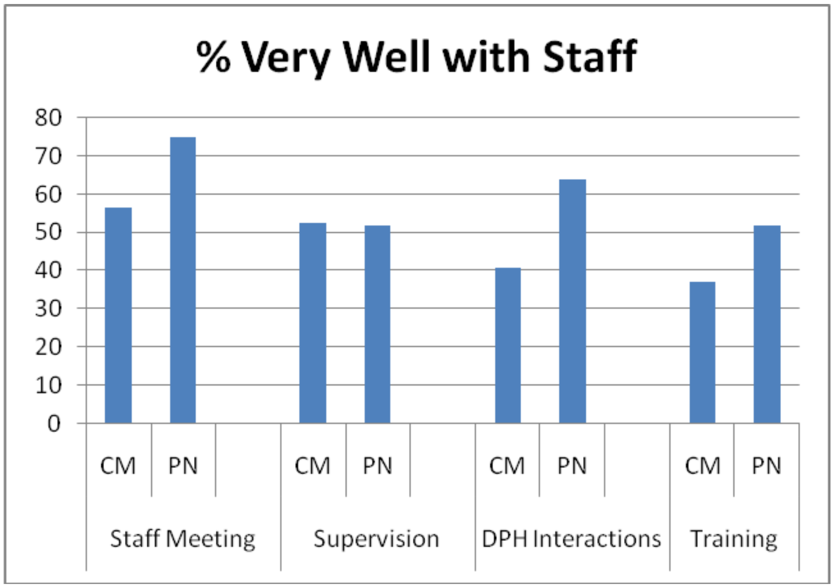
Coordinating services with others in the health care outside the Care Coordination Program was not always successful.

> it's hard to get doctors and providers to remember who we are and that the program is free and that we are still here, every time we go "oh you're still here, who are you?"

Patient navigators rated several program personnel activities as being carried out better than did program case managers (Exhibit 16). More than two-thirds of patient navigators rated staff meetings as being carried out very well, compared to just over half of the case managers, almost two-thirds of the patient navigators rated interactions with DPH staff as going very well, compared to 50% of the case managers, and half of the patient navigators rated training about work as going “very well,” compared to one-third of the case managers. Half of both groups rated staff supervision as being carried out very well.

Exhibit 16

Staff Ratings of Staff Activities



Feelings about the Work

Job satisfaction was very high among both case managers and patient navigators, with almost two-thirds of both groups reporting that they were “very” satisfied with their job overall and even more in both groups rating themselves as very satisfied with their coworkers and their supervisor (Exhibit 17). However, the level of satisfaction with other facets of the job varied between the two groups. Ratings of relations with patients elicited the highest levels of satisfaction in both groups, but more among patient navigators (86%) than among case managers (74%). Patient navigators were also more satisfied with case managers with the work itself (71% compared to 52%), but in contrast, they were relatively dissatisfied with their salaries (15% compared to 30% were very satisfied) and their experiences with other agencies (30% compared to 59% were very satisfied).

Exhibit 17

Staff Job Satisfaction

Satisfaction		
% very satisfied (=1)	CM	PN
Job Overall	60.9	64.3
coworkers	66.7	72.4
salary	30.4	14.8
the work itself	52.2	71.4
supervisor	69.6	67.9
patients	73.9	85.7
other agencies	59.1	29.6

As indicated by the high levels of satisfaction patient contact elicited from both case managers and patient navigators, relations with patients were often the basis for satisfaction with the job overall.

> I'm very satisfied. I love what I do. …. I mean, I can say somewhat satisfied if I'm thinking of all the things that have nothing to do with my patients and what I do but because the patient is the most important thing for me – very satisfied.
>
> If I actually connect with someone and we can get a plan going it feels wonderful.
>
> I like what I do. I like working with the patients in the community, knowing that I'm giving back to them in some way and that they

> have that one person that they feel comfortable with is coming. …you know, word-of-mouth of other patients coming, you know. They told me you helped my sister with this and that. All right, great, sure. Just sign right here and enroll in CCP and I can help you.

One case manager found satisfaction in the challenge of figuring out patients' medical problems.

> it is more investigation. It's a little bit more like Sherlock Holmes. You have to be really attentive to detail like that and you have to really focus. It was a little more medical and more challenging so I really like that. I really enjoy that piece of it and no two cases are ever the same.

Another felt that she had done a good in helping a patient to assert herself in relations with her family.

> she is now more able to assert herself, umm she had been… when her dad was alive she was really her dad's caregiver … I was talking with her last summer … she was feeling kind of railroaded…. Now she's …more able to say 'no' and she's more able to make choices that are healthier for her both physically and emotionally. …A few days after Dad died she went with her sister to an adjacent town and filled out an application. I'm like, 'you rock!'

However, case managers were particularly likely to report that the pressure of their other work responsibilities constrained the time they had available for the Care Coordination Program.

> we have to have blocks of time and not just an hour a week because that's, that's nothing, you could do maybe two chart reviews in an hour depending on the population, so dedicated time for nurses to work on their case management right now we don't have it.
>
> when we are short-staffed which frequently happens, that's the first thing we push out of the way, so it's hard to dedicate, it's hard to get the time to do it. I mean it's a good idea, it's you know we have the tools to do it, we have the education to do it but we don't have the time to do it. Time is our big problem.

In spite of these different patterns of satisfaction and dissatisfaction, patient navigators and case managers were committed to their current jobs, with fewer than one in five in both groups reporting they were very likely to leave (Exhibit 18). Half (patient navigators) or more (case managers) said they were not likely at all to leave their job.

Exhibit 18
Staff Likelihood of Leaving the Job

Likely to leave job	CM%	PN%
Very likely	18.2	17.9
Moderate likely	4.5	17.9
Not very likely	18.2	14.3
Not likely at all	59.1	50.0

> I don’t mean to brag about this, but I always feel satisfied. I feel… it’s about conscience. I could not go without knowing that I did not attempt beyond of my capacity to attempt to outreach a patient, keep the patient, help the patient overcome the barriers to complete this test that can prevent people dying from colon cancer. So, it’s my conscience. I cannot go home without doing my last outreach phone call, you know? So, I have a plan. If I don’t get them on the telephone I get them in person, but I get them!

Both case managers and patient navigators rated positively their feelings about their service work, with average ratings of both “impact on patient well-being” and feeling “gratified” at work at between 7 and 9 on a 10-point scale (Exhibit 19).

Statements by both case managers and patient navigators illustrate the bases of these feelings of satisfaction.

> I got to meet her because she was sick …and they couldn't get in touch with her. Even if we call her with the interpreter, she doesn't pick up. …one day I—one of the nurses who does patient case management here asked me to call the patient. … so as I was talking to her over the phone, I was asking her the questions and then she was answering me. …And she finally came in and she was asking to see me, but I wasn't sure why she was asking to see

me. So, I went. She was like, oh, thank you. You were so nice over the phone to me. … So, actually, that made me happy.

like most of the time it makes me feel good because this is a screening that it's gonna tell them that they are fine or they have a problem that we can help them to resolve the problem.

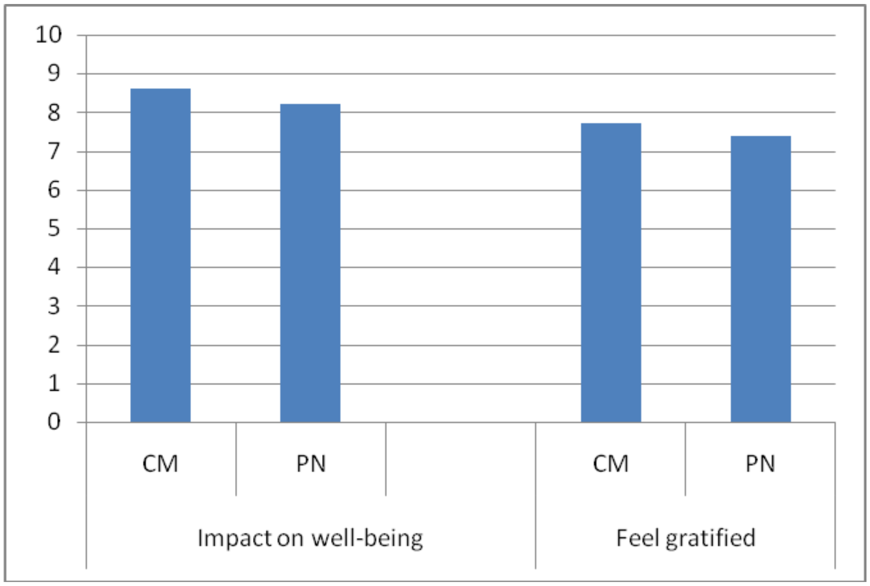
… And I realized that it was almost time for the appointment so I grabbed the paper, I called the hospital, I said, 'we have the patient here and she didn't know it was at the hospital but I will try to send her, will you wait for her?' and they said, 'oh, yeah we will wait for her'. … she looked at me and said, 'I cannot take a taxi because I only have two dollars' and I said, 'well, you know, I will be more than happy to pay you the taxi if you want to go'. But then, a nurse came in and said, you know we can get a voucher for her for a taxi so we gave her a voucher and she went. Like a month later she called me and she said, 'I don't know if you remember me but I was the person that you helped the other day go to the hospital and I just wanted to thank you because I have an abnormal results and I had a biopsy two weeks ago and I have breast cancer.' So this is one of the things that made me really happy at what I do…

I enjoy working in the program, its basically helped me to learn about giving them the resources that they really need, sharing information, that's really what I love about my job is talking to

> patients and giving them the resources that they need to help themselves and also I love interpreting.

Exhibit 19

Staff Feelings at Work



Patient Interviews

Patient Background

Patients varied in age from 24 to 72, with an average (mean) of 53 years old, and they were mostly women (81%). Educational backgrounds were diverse, with about one quarter who did not complete high school, one-third who were high school graduates, and more than one-third who had at least some college (Exhibit 20). However, only one in five had completed a degree from a four year college. Neither average age nor educational level differed between men and women in the program.

Exhibit 20
Patient Educational Level

Level of Education	**%**
8th grade or less	17
Some High School	12
HS Graduate or GED	35
Some College or 2-year Degree	18
4-year College Degree	12
Over a 4-year College Degree	7
Total*	101%
Base N	383

*Does not total 100 due to rounding error.

About one-quarter of the respondents had never been married and just over one-third were currently married (Exhibit 21). One in five was divorced, with the rest being either separated or divorced at the time of the survey. Marital status differed between women and men in the program, with men more likely to be currently married and women more likely to be separated or widowed.

Exhibit 21
Patient Marital Status

Marital Status	**%**	**Male**	**Female**
Married	36	44	35
Never Married	24	3	15
Divorced	20	18	20
Separated	13	3	8
Widowed	7	31	23

Total	100%	99%	101%
Base N	383	61	322

Marital status itself does not adequately describe the living situation of the respondents. Half of the respondents were living with dependent children and almost 60 percent were living with a partner (Exhibit 22). Taking into account both of these two features of living situation identifies 13 percent of the sample as single parents with dependent children. Women in the program were much more likely to have dependent children than were men, whether or not they lived with a partner.

Exhibit 22

Patient Living Status, including Children

Living Status including Children	**%**	**Male**	**Female**
Partner, No Children	22	46	18
Partner, Children	37	21	40
Alone, No Children	28	28	27
Alone, Children	13	5	15
Total	100%	100%	100%
Base N	383	57	318

Half of the respondents were working, although only about half of those were working full-time; most of the rest were either not working or retired, with just 15% "looking for work" (unemployed) (Exhibit 23). Men and women in the program had similar rates of employment, although men were somewhat more likely to have a full-time rather than part-time job and also to be looking for work.

Exhibit 23

Patient Employment Status

Employment Status	**%**	**Male**	**Female**
Full time	23	26	22
Part Time	27	18	29
Not working	19	16	20
Looking	14	20	12
Retired	17	20	16
Total	100%	100%	99%
Base N	383	61	322

Summary

Each of these personal characteristics is a potential influence on health behaviors and orientations, and so also on the differences in health needs that may be encountered at each health center. Health problems vary with age, parental status, and gender, while education is related to health care orientations and behaviors and to resources that facilitate health services. Both single parenthood and employment can limit availability for health care appointments and employment status may be associated with income, insurance, and other resources that shape use of the health care system.

Ethnicity, Language, and Immigration Status

Care Coordination patients are distinguished by ethnic and linguistic diversity and by their immigrant status. Almost half of the patients identified themselves as Hispanic and just one-quarter as white, with the remaining quarter being divided between those who identified themselves as black or African American and of some "other" race (Exhibit 24).

Exhibit 24

Patient Ethnicity

Ethnicity	**%**
White	26
Hispanic, any race	46
Black	13
Other	15
Total	100%
Base N	383

The majority of patients were born outside of the United States, with the distribution roughly equal between South America, Central America, the Caribbean islands and some other location (Exhibit 25).

Exhibit 25

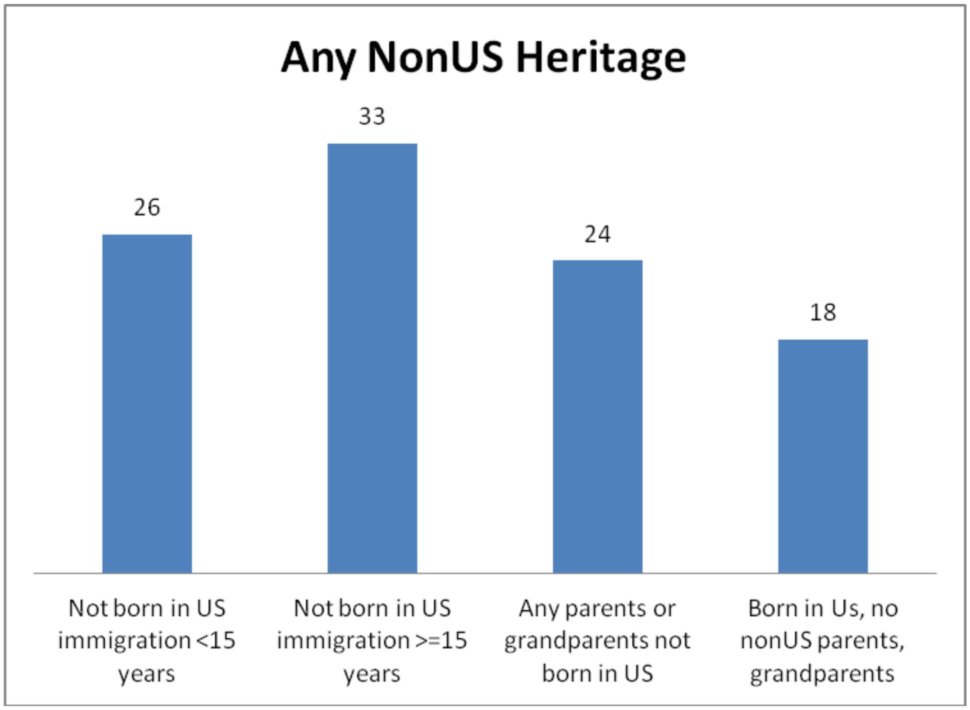
Patient Country of Origin

Country of Origin	**%**
United States	41
South America	15
Central America	12
Caribbean Islands	19
Other	13
Total	100%
Base N	383

Immigration status created another important distinction among Care Coordination patients. Only one quarter of respondents were the product of families that had been in the United States for at least four generations (Exhibit 26). Fewer than one in five were a second- or third-generation American, while three in five (59%) were first generation immigrants. The first generation immigrants were almost equally divided between those who had been in the US for at least 15 years and those who had come to the US more recently.

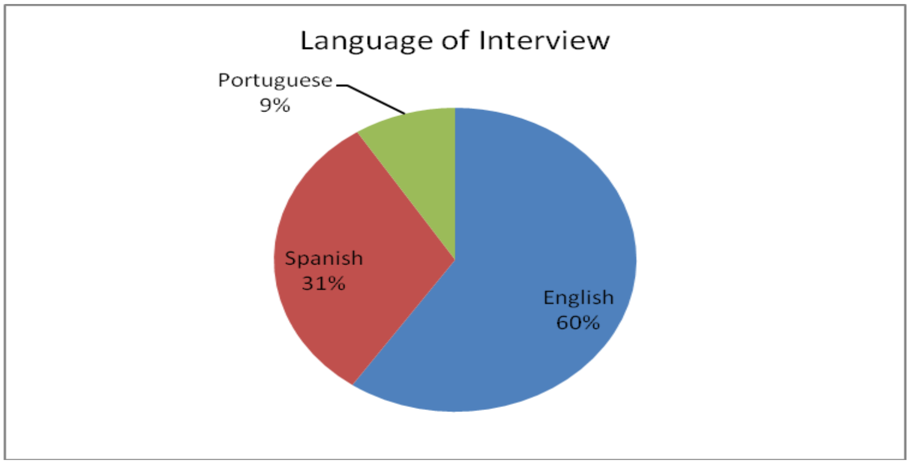
Exhibit 26

Patient Immigrant Status



Care Coordination patients also varied in linguistic preference. Six in ten were interviewed in English, one-third chose to be interviewed in Spanish, and just 9% requested an interview in Portuguese (Exhibit 27).

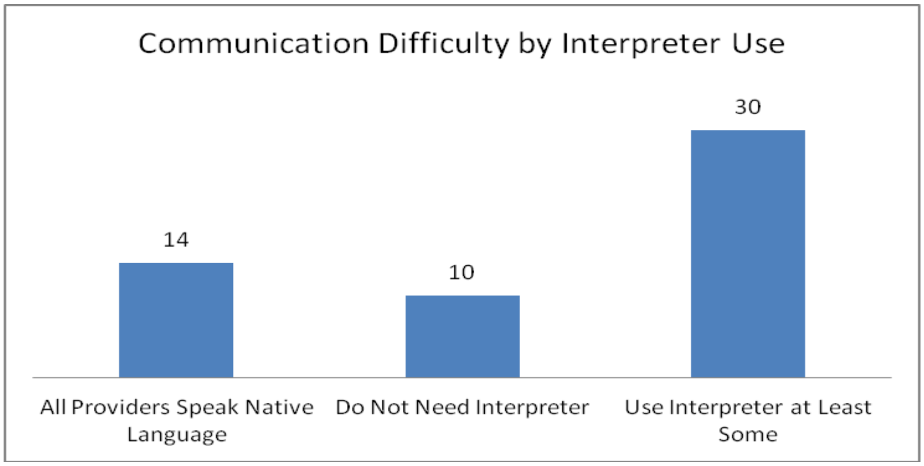
Exhibit 27
Patient Linguistic Preference



Examination of the relationships among the indicators of ethnicity, language, and immigration status indicates that they do not entirely overlap and so must each be considered in the analysis. Nineteen percent of the patients for whom English was not their primary language reported difficulty speaking with or understanding their health care provider due to language problems. All of the patients with language difficulties were first generation immigrants, but the percentage who acknowledged language difficulties did not vary with length of time in the U.S. Similarly, all who chose not to be interviewed in English were first generation immigrants, but the decision not to be interviewed in English among first generation immigrants did not vary with their length of time in the U.S. The one linguistic difference in relation to recency of immigration was that Portuguese speakers were much more likely to be recent immigrants. (tables not shown)

Language difficulties were concentrated among those whose primary language was not English (50% of the total sample) and who used interpreters at least some (36%). Among those respondents for whom English was not their primary language, about one-third of those who used an interpreter at least some of the time reported communication difficulties, compared to just 10-14% of those whose providers all spoke their native language or who said they did not use an interpreter (Exhibit 28).

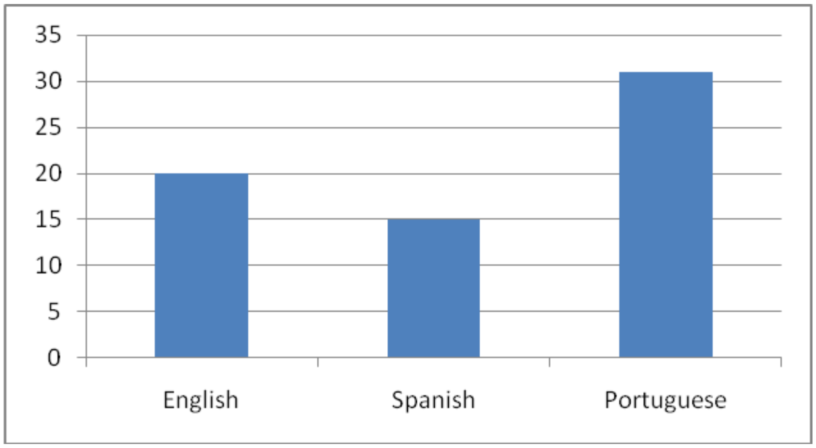
Exhibit 28



Communication difficulties with health care providers were much more prevalent among Portuguese speakers than among English or Spanish speakers (Exhibit 29).

Exhibit 29

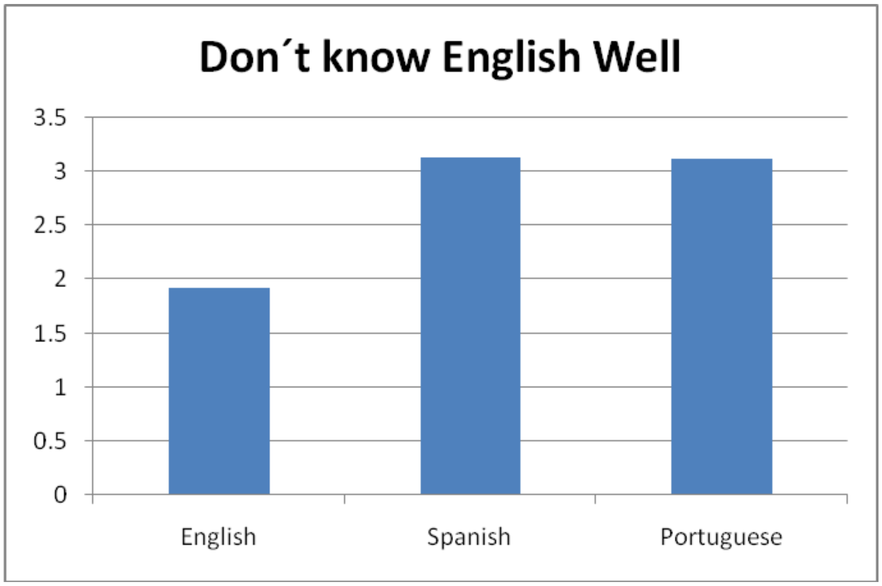
Communication Difficulty by Language of Interview



These greater communication difficulties for Portuguese speakers were not due to self-reported poorer English abilities than Spanish speakers (Exhibit 30).

Exhibit 30

Knowledge of English by Linguistic Preference



Instead, Portuguese speakers were much less likely to have all health care providers who spoke their native language than Spanish speakers and were much more likely to use an interpreter than Spanish speakers (Exhibit 31).

Exhibit 31

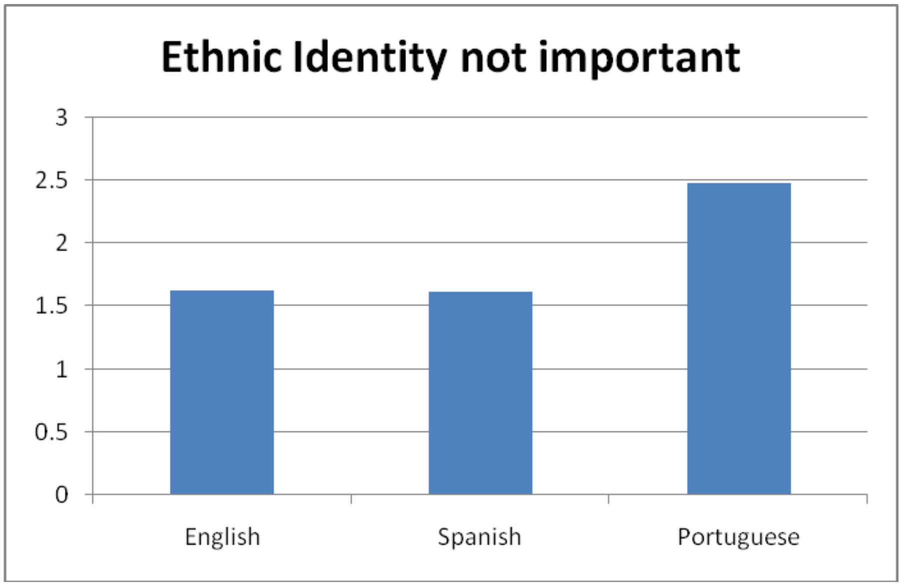
Use of Health Care Interpreter by Linguistic Preference

	English	**Spanish**	**Portuguese**
All Speak Native Language	53.70%	46.60%	11.40%
Do not use interpreter	46.30%	13.80%	20%
Use interpreter at least some	0%	39.70%	68.60%
Total	100%	100%	100%
Base N	41	116	35

In spite of their greater language problems in interacting with health care providers, Portuguese speakers felt that it was less important for health care providers to understand their ethnicity, national origins, traditions and values, or culture than did Spanish or English speakers (Exhibit 32).

Exhibit 32

Importance of Ethnic Identity by Linguistic Preference



The most recent immigrants, who are the youngest (50 years on average compared to 53 for the total sample), were less likely to feel they could speak English well and also less likely to feel that their ethnic identity was important. The lesser importance of ethnic identity for the Portuguese speakers is largely explained by their younger average age.

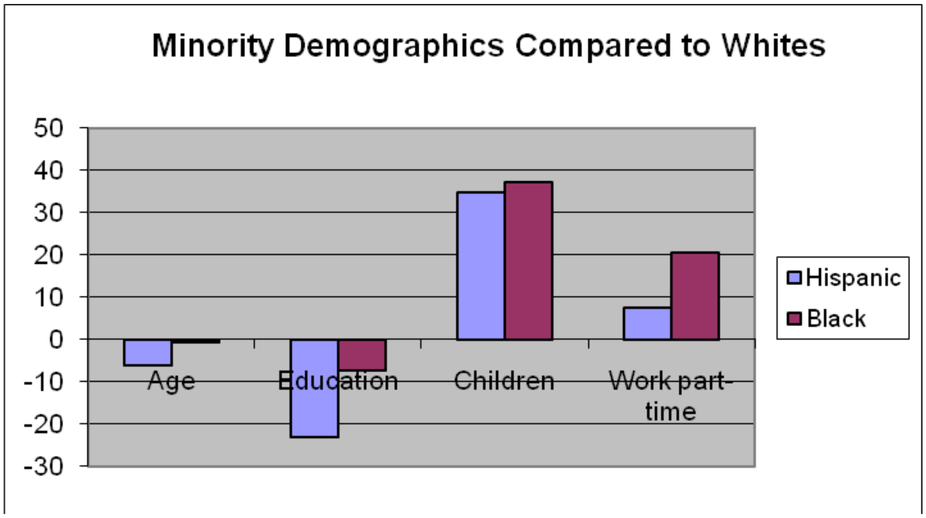
Summary

Care Coordination survey respondents were diverse in their ethnic and immigrant backgrounds and mostly from traditionally underserved groups. Almost half were Hispanic, more than half were born outside of the U.S., and three-fourths were in first-, second-, or third-generation immigrant families. Although most of the interviews were conducted in English, many of these interviews among first-generation immigrants were in Spanish (one-third) or Portuguese (one-tenth). Difficulties in communicating with health care providers were reported by many who used interpreters as well as by those who spoke Portuguese. Overall, the survey responses suggest that Portuguese speakers had fewer health care providers who spoke their language, and so had to rely more on health care interpreters. In spite of this disadvantage in communication, Portuguese speakers attached less importance to their ethnic identity than did Spanish speakers.

The Relationship of Ethnicity, Language to Other Characteristics

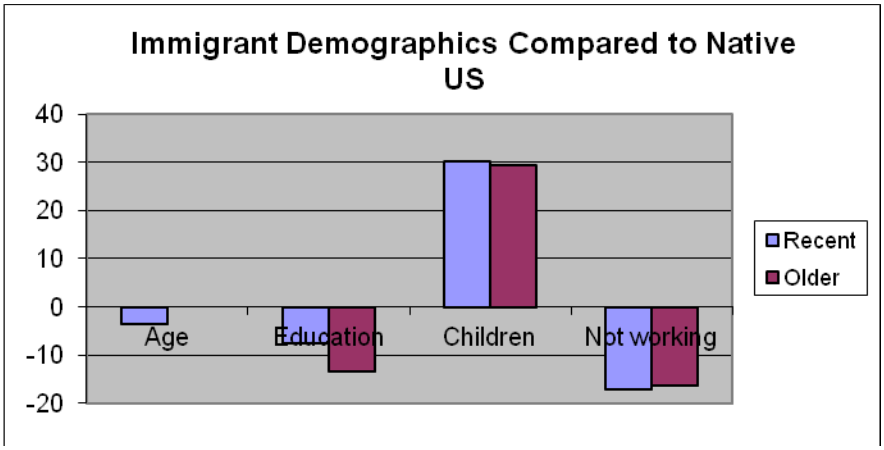
Patients distinguished by ethnicity and language also differed in some other important sociodemographic characteristics. Hispanics and African Americans were both much more likely to have dependent children than whites and also to have less education compared to whites (Exhibit 33). In addition, Hispanics tended to be younger than whites, while blacks were more likely to be working part-time rather than full-time.

Exhibit 33



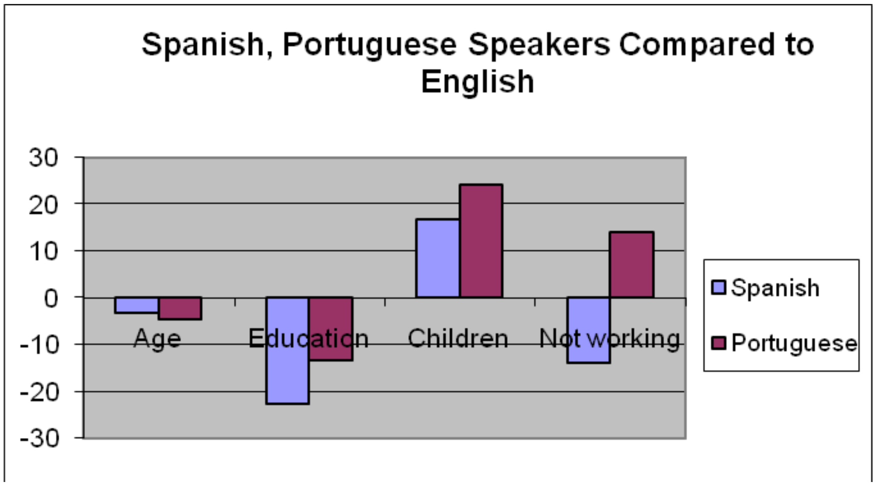
Largely similar demographic differences appear when comparing groups distinguished by immigration status (Exhibit 34). First generation immigrants had more children at home, on average, and were more likely to not be working compared to native U.S. residents, while they also tended to be less educated. Those who had immigrated within the preceding 15 years also tended to be younger.

Exhibit 34



Those who spoke Spanish and Portuguese in the interview differed from English speakers in the same ways as did first generation immigrants, but there was one important difference between those who spoke Spanish and those who spoke Portuguese: Spanish speakers were less likely not to be working compared to English speakers, while Portuguese speakers were more likely not to be working (Exhibit 35).

Exhibit 35



Summary

These sociodemographic differences may help to explain different health behaviors and orientations between segments of the Care Coordination patient population that differ in ethnicity, language, and immigration status. While younger age may be associated with fewer health problems, fewer years of education and multiple part-time jobs among Hispanics and immigrants could cause problems for obtaining and using health care services. The greater presence of dependent children at home could also result in variation in both health problems and ease of accessing health care services. There were no appreciable differences related to ethnicity, language, and immigration status between men and women in the program.

Health Status and Concerns

There were many indications of health problems among Care Coordination patients. Only about one-quarter rated their health as excellent or very good, although a majority rated their health as at least "good" (Exhibit 36). Women tended to report their overall health as somewhat better than men.

Exhibit 36
Patient Self-Rated General Health

General Health	**%**	**Male**	**Female**
Excellent	11	7	12
Very Good	17	12	18
Good	31	43	29
Fair	33	25	34
Poor	8	15	7
Total	100%	102%	100%
Base N	383	61	322

However, only 15 percent felt that their health problems had gotten worse in the preceding year, as compared to more than twice as many who said their health problems had gotten better (Exhibit 37).

Exhibit 37

Patient Assessment of Change in Health Problems

Health Problems Gotten …	**%**
Better	34
About the Same	52
Worse	15
Total *	101%
Base N	383

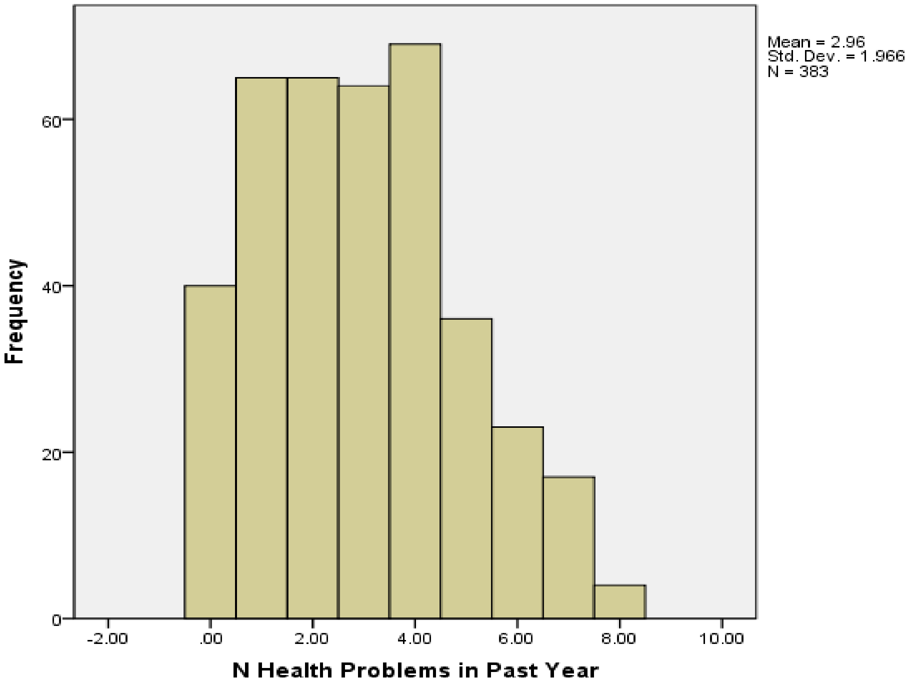
*Does not total 100 due to rounding error.

Of course, answers to these two general questions about health were related to each other. Just over one-third of those who said their health had gotten better or had stayed the same in the past year rated their current health status as “fair” or “poor,” compared to almost two-thirds of those who said their health problems had gotten worse (table not shown).

All but ten percent of the respondents reported having had at least one health problem in the past year (Exhibit 38). About one in six reported just one health problem, exactly two problems, three problems, and four problems, for a total of 85% who reported 1-4 health problems. The average (mean) number of health problems was three; out of a total of eleven problems offered in a list, the maximum number of health problems reported in the past year was eight.

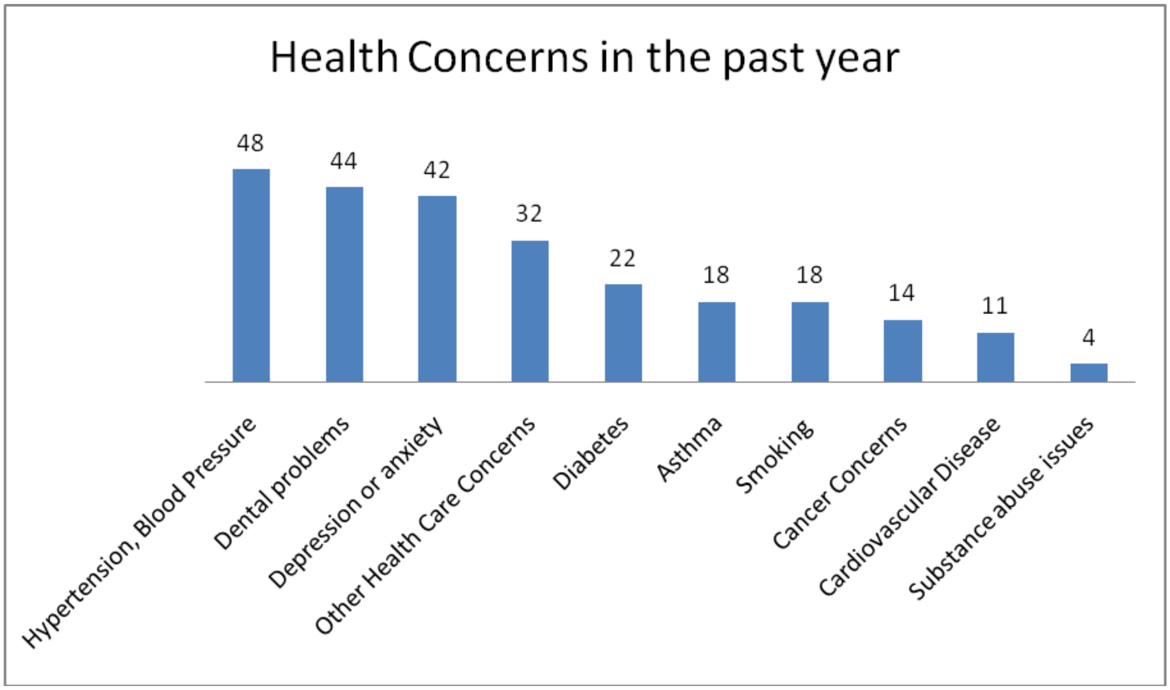
Exhibit 38

Number of Health Problems



The most common health problems reported were hypertension/high blood pressure, dental problems, and depression or anxiety (42-48% each), with “other health care concerns” indicated by about one-third (Exhibit 39). Diabetes, asthma, and smoking were each reported by about one in five, while cancer concerns and cardiovascular disease were only mentioned by about one-tenth each. Substance abuse issues were even less common.

Exhibit 39



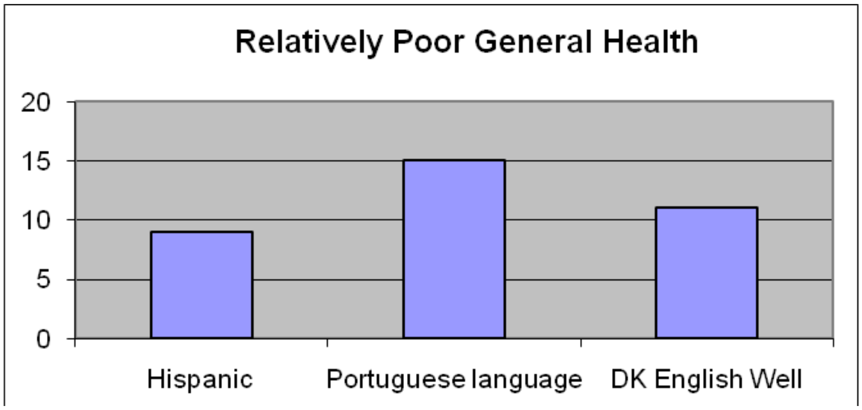
Health Status in relation to Ethnicity, Immigration, Language

Patients who differed in ethnicity, immigration status, or linguistic preference also differed in some important health status indicators, but these health differences were not consistent between ethnic, immigrant or linguistic groups nor did they reflect a consistent minority disadvantage.

The most important ethnic/linguistic health difference was in self-reported overall health: Hispanics and Portuguese speakers, as well as those who said they did not know English well, tended to report worse health than non-Hispanics and those who spoke English or felt they knew English well (Exhibit 40). In addition, recent immigrants were less likely to say that their health had worsened in the past year than were less recent immigrants or those born in the U.S. (table not shown).

Exhibit 40

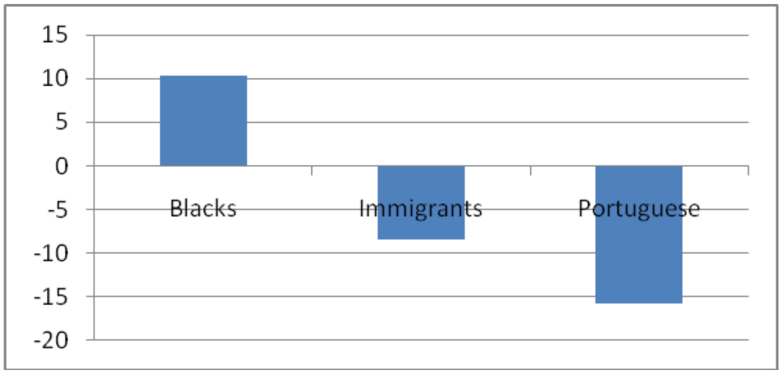
Overall Health by Ethnicity and Language



The prevalence of several specific health problems varied with patient ethnicity, language, or immigration status. Asthma was more often reported by blacks than by whites, and less often by immigrants and those who spoke Portuguese compared to those born in the U.S. and either Spanish or English speakers (Exhibit 41). By contrast, both cancer concerns and CVD were about 15 percentage points more likely to be reported by Portuguese speakers, as were dental problems (22 percentage points), than by Spanish or English speakers (table not shown). Portuguese speakers were also more likely (by 16 percentage points) to report “other” health problems than were whites. Blacks were less likely to report other health problems (18 percentage points less than whites).

Exhibit 41

Asthma Prevalence* by Race, Immigration Status, Language

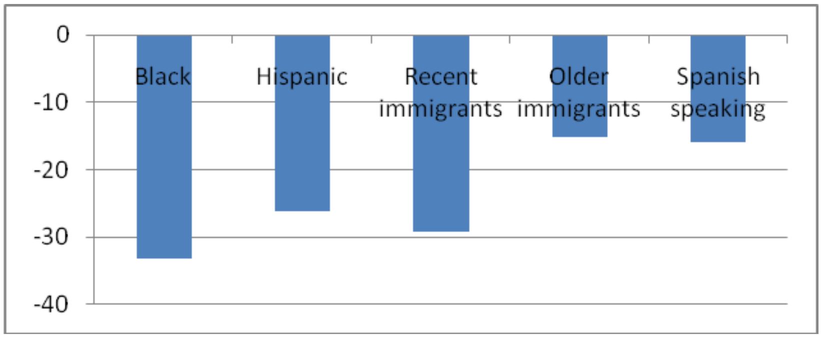


*Compared to whites, 4th+ generation Americans, English speakers.

Depression was much more often reported by white English speakers born in the U.S. than by blacks, Hispanics, immigrants, or Spanish speakers (Exhibit 42).

Exhibit 42

Depression Prevalence* by Race, Immigration Status, Language

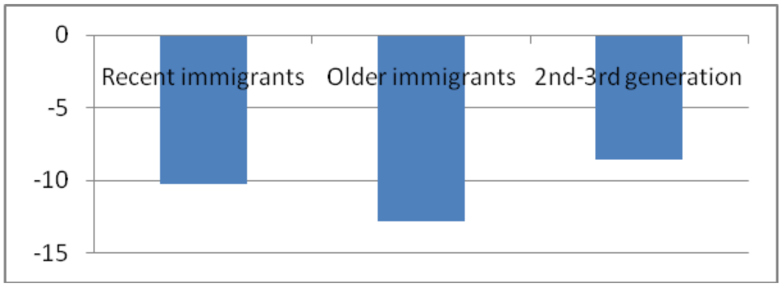


*Compared to whites, 4th+ generation Americans, English speakers.

Reports of diabetes were more common among recent immigrants than among those without an immigrant background, but immigrants and even those in 2nd or 3rd generation immigrant families were less likely to report substance abuse problems than those without an immigrant background (Exhibit 43).

Exhibit 43

Substance Abuse Prevalence* by Immigration Status

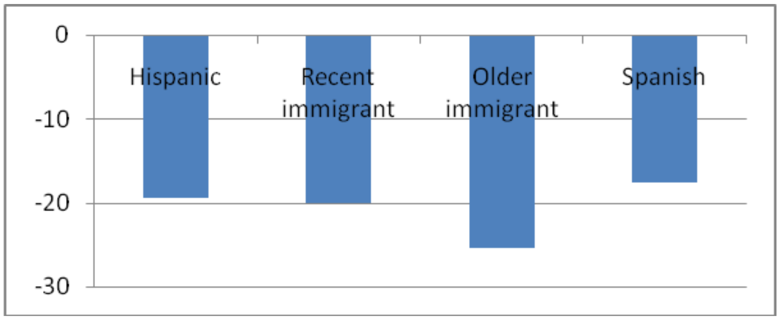


*Compared to whites, 4th+ generation Americans, English speakers.

Smoking was also much less common among the related groups of immigrants, Hispanics, and Spanish speakers than it was among non-immigrants, whites, English speakers.

Exhibit 44

Smoking Prevalence* by Immigration Status



*Compared to whites, 4th+ generation Americans, English speakers.

Summary

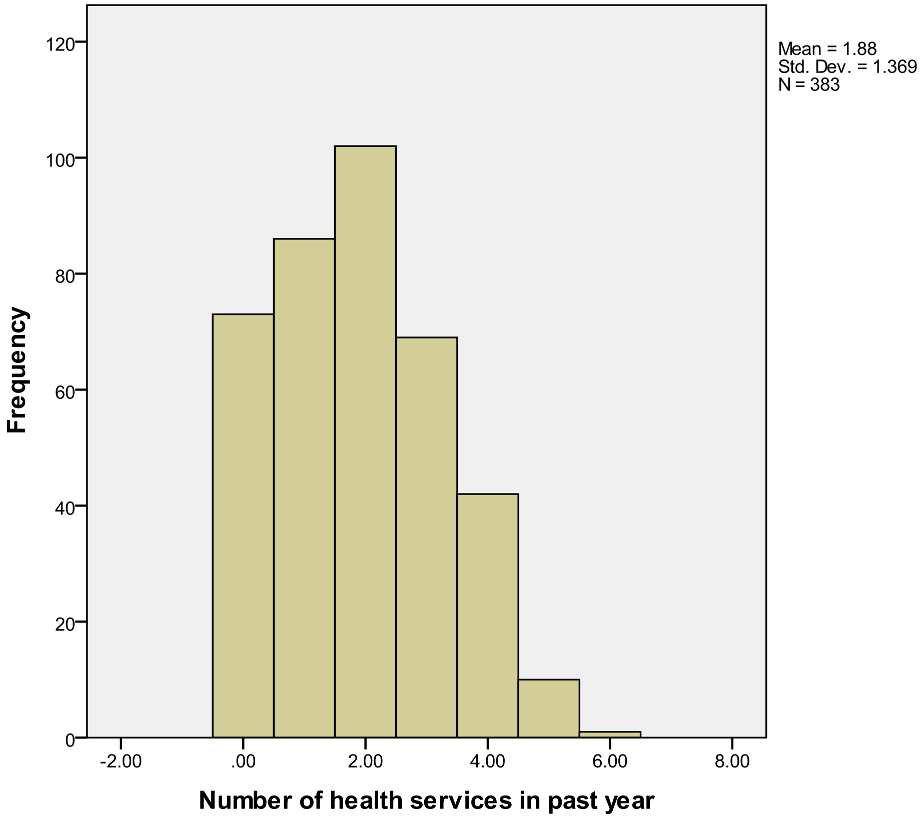
Almost all the respondents reported one or more health problems and their rating of their health overall tended not to be high, although more felt their health had improved in the past year than felt it had worsened. The most common specific health concerns were hypertension/high blood pressure and depression, as well as dental problems. Variation in some of these health indicators was patterned by ethnicity, language, and immigrant status. Hispanics, Portuguese speakers, and those who rated themselves as less capable in English assessed their health as poorer than others, but this same pattern did not occur with respect to specific health problems. Immigrants reported lower rates of asthma, depression, substance abuse, and less smoking than did non-immigrants; some of these health advantages also appeared when Hispanics, Spanish speakers, and/or Portuguese speakers were compared to whites or English speakers. African American respondents were more likely to report asthma than white respondents, while white respondents, non-immigrants, and English speakers were all more likely to be depressed than their ethnic, migrant, and linguistic counterparts.

Health Care Services

Respondents had received, on average, 1.9 health services in the past year, with many having received only one (22%) or no (19%) health services (Exhibit 45).

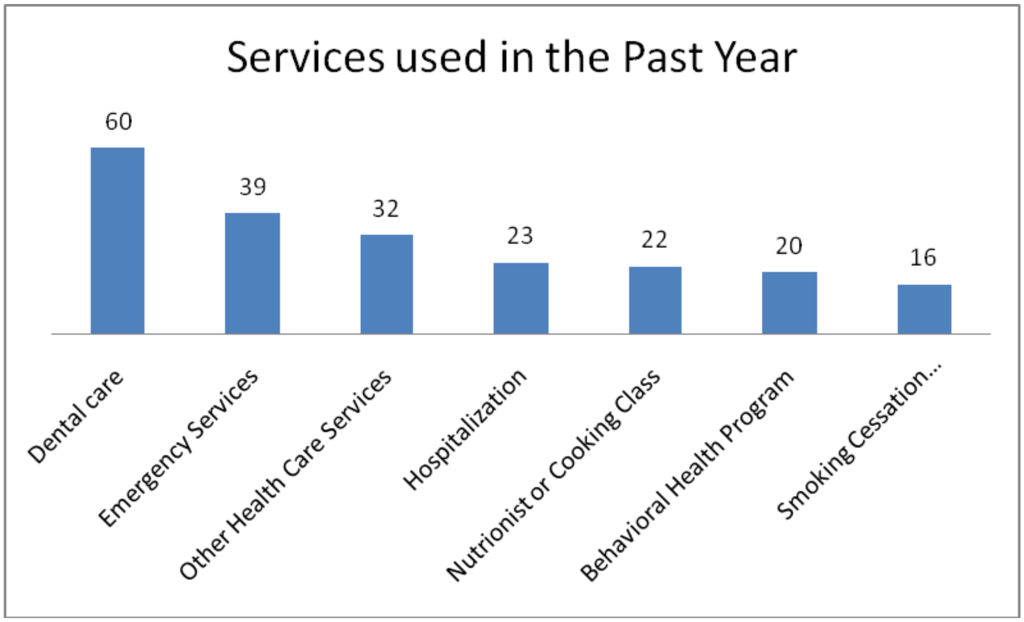
Exhibit 45

Number of Health Care Services Received



Dental services were the most common health care services received in the past year (60%) and many had received some type of emergency services (39%) (Exhibit 46). About one in five had received such specific health services as programs in nutrition, behavioral health, or smoking cessation, or had been hospitalized. Women (63%) were more likely to have received dental care in the past year than were men (40%), but did not differ from men in the frequency with which they had used the other health services mentioned.

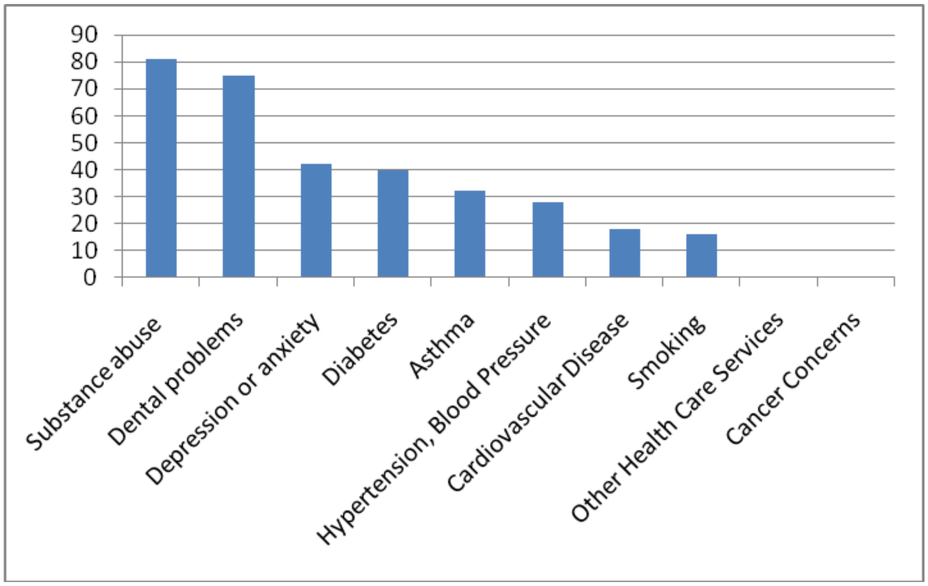
Exhibit 46



Patients with several specific health problems were more likely to have received services designed for these health problems (Exhibit 47). Of the small number of patients who reported a substance abuse problem, 80% had received behavioral health services, as had 40% of the much larger number who reported depression or anxiety. Three-quarters of those who reported dental problems had received dental services. Four in ten of those with diabetes had received nutrition or cooking classes, as had one-third of those with asthma, and about as many with hypertension, but only 18% of those with CVD. Only 16% of the regular smokers had participated in a smoking cessation class. There were no specific services in this list targeted to cancer concerns, or, of course, to "other" health concerns.

Exhibit 47

Specific Health Services Used for Health Problems

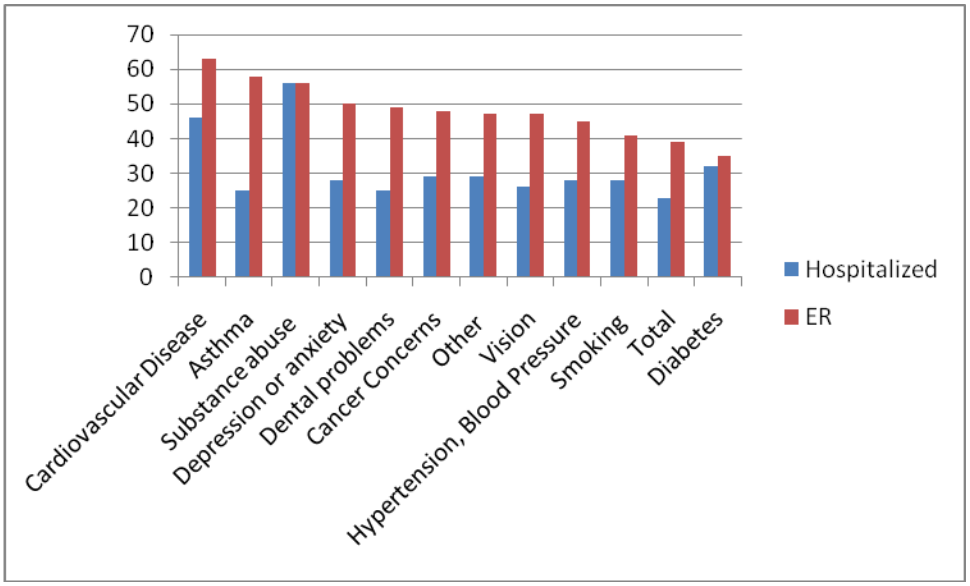


Although specific services for cancer concerns were not included in the list of possible services used in the phone survey, the DPH service database includes records of exams and their outcomes for breast and cervical cancer screening. Just 10.5% of the phone survey sample had not had any breast exam, compared to 51% who had had one breast concern (mostly mammograms) and 38.5% who had had more than one (percentages similar to those for the patient population as a whole. In contrast, about two-thirds (67.8%) had not had any cervical cancer screening exam, compared to 21.5% who had had one such test and about 10% who had had more than one (again, similar to the distribution in the population). Of the total number of cases that were followed based on initial test results in the patient population; 1.5% were diagnosed with cancer (none in the phone survey sample had been diagnosed with cancer).

The specific health problems varied markedly in their association with hospitalization and use of emergency services in the past year (Exhibit 48). About 60% of those who reported CVD, asthma, or substance abuse problems had used emergency services in the past year, as had about half of those with depression or anxiety, dental problems, or cancer concerns, compared to a 39% overall rate of emergency services use. Hospitalization was most likely among those with substance abuse problems and CVD (about half, compared to an overall rate of 23%).

Exhibit 48

Hospitalization & ER Use by Specific Health Problems

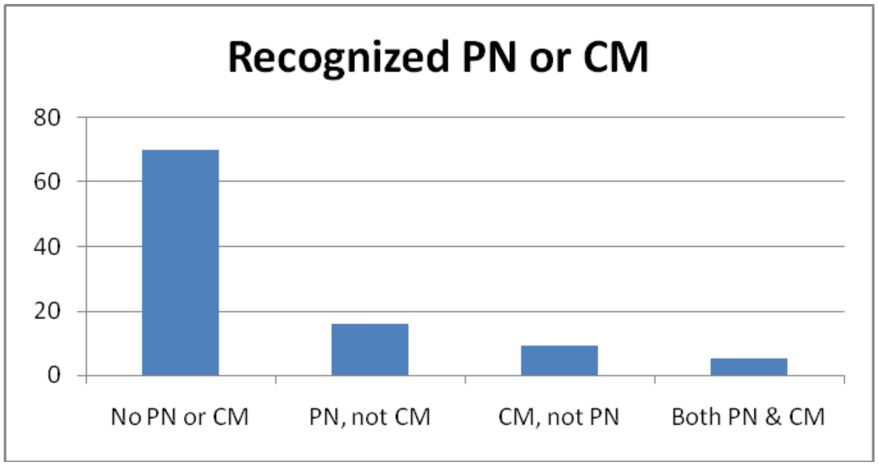


Only three in ten of the respondents were aware of having received services from either a patient navigator or case manager (Exhibit 49). Of these, 16% were aware of services provided by a patient navigator only, nine percent were aware of services provided by a case manager only, and just five percent were aware of having received services from both.

The in-person patient interviews also highlighted the importance of patient navigators' help with transportation, providing vouchers for a visit to a doctor outside the clinic, clearing up insurance problems, making calls to check on the patient, and scheduling appointments.

Therapists were available when needed and were highly regarded. Just one of the patients interviewed in-person had a strong, ongoing relationship with her patient navigator, but her experiences illusrrate how valuable that relationship can be. This patient was an immigrant who had been diagnosed with breast cancer but initially had no insurance. The patient navigator was "extremely supportive and helpful, " driving her to appointments, following up about her medications, and advocating with providers.

Exhibit 49

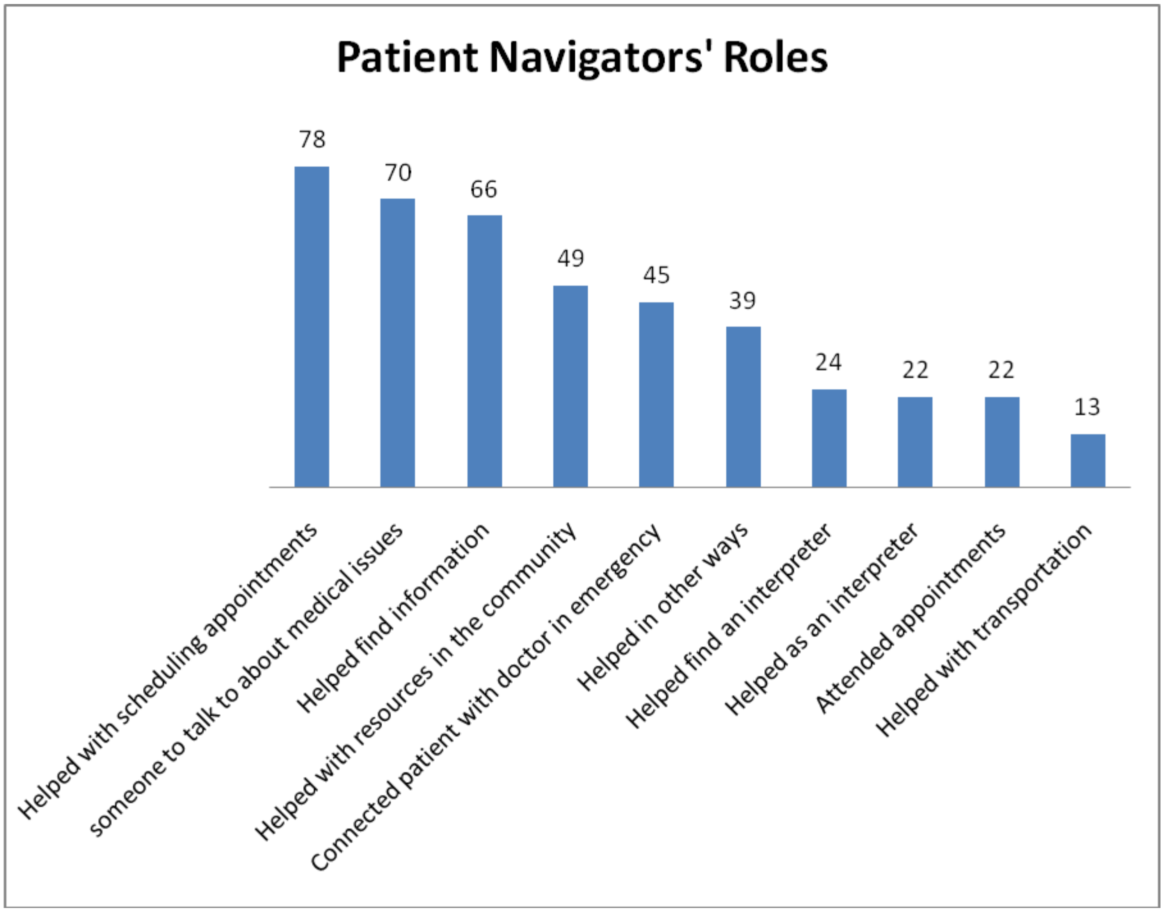


Among the health problems, only patients who had had cancer concerns and diabetes were more likely to report a connection with a patient navigator (31% and 28%, respectively) than others (20%). However, patients who reported having been depressed in the past year reported having talked with their patient navigator quite a bit more (6.2 times) compared to those who did not report depression in the past year (3.6 times). No other health problem was associated with the frequency of having talked to a patient navigator, but patients with asthma had received more types of help from their patient navigator. Compared to the overall rate of 15%, patients were more likely to report having a case manager if they had had cancer concerns (24%), depression (20%), or dental problems (19%).

Patients were mostly similar in their use of health services, whether or not they were aware of having a patient navigator or had been assigned a case manager. However, those with a case manager were more likely to have been hospitalized and used emergency services in the past year, while those who were aware of having had a patient navigator were more likely to have used "other" health services. (Table not shown.)

Whatever their health problems, the 77 respondents who were aware of having had a patient navigator reported having received a variety of services (Exhibit 50). Help with scheduling appointments, providing someone to talk with about medical issues, and helping to find information were each reported by around two-thirds of those who were aware of having received any patient navigator services. About half had received help with securing resources in the community or with emergency needs, while almost one quarter had received help with an interpreter or with attending appointments. Receiving help with transportation was least common (13%), although 39% reported having received some other type of help.

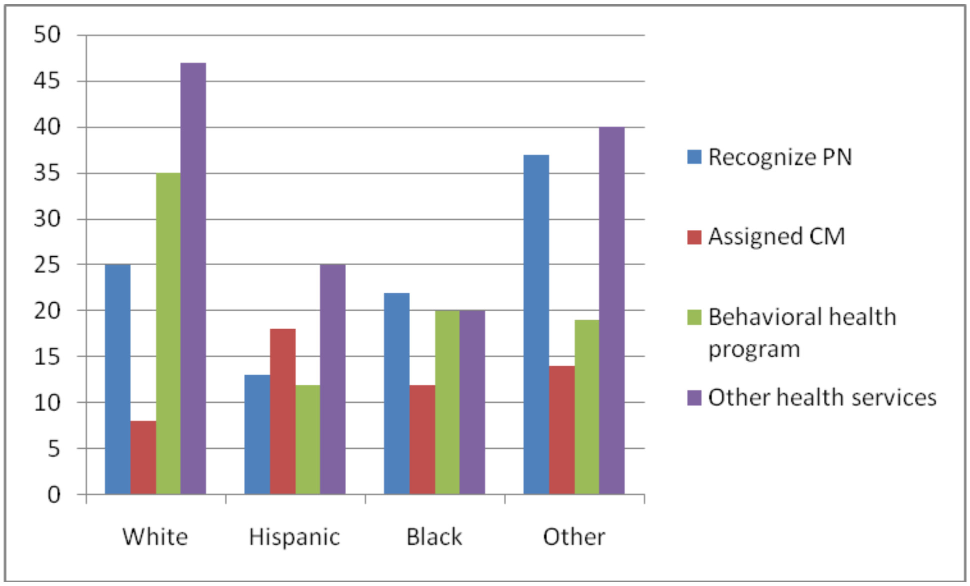
Exhibit 50



Patterns of health care service use differed with the indicators of ethnicity, immigrant status, and language preference (Exhibit 51). Hispanics were less likely to recognize a patient navigator's name than were whites, blacks, or those who identified with another racial or ethnic group. There were no ethnic differences in likelihood of having been assigned a case manager, but whites were much more likely to have participated in a behavioral health program and both whites and those in the "other" ethnic/racial group were more likely to have used other health services than were Hispanics or blacks.

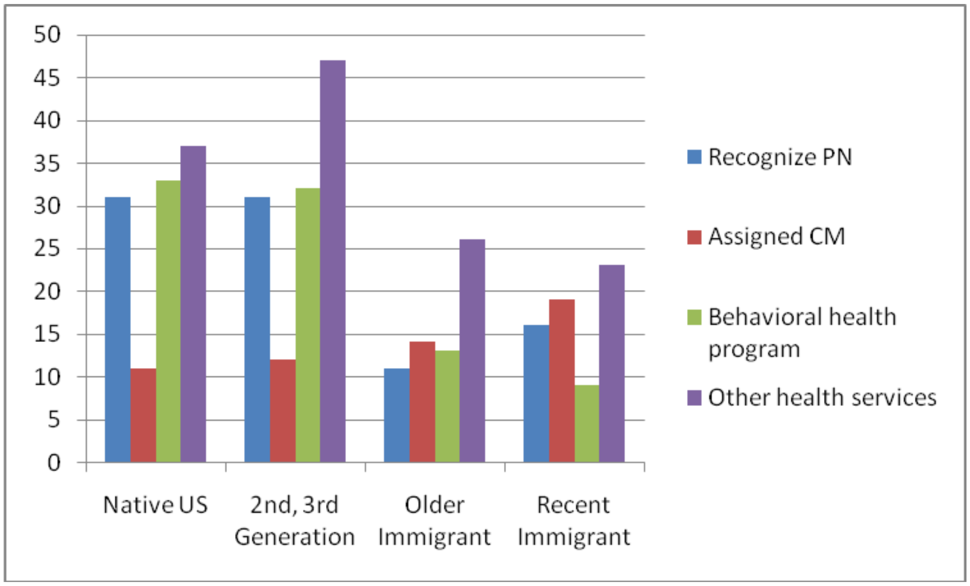
Exhibit 51

Health Care Service Use by Ethnicity, Immigrant Status, Language Preference



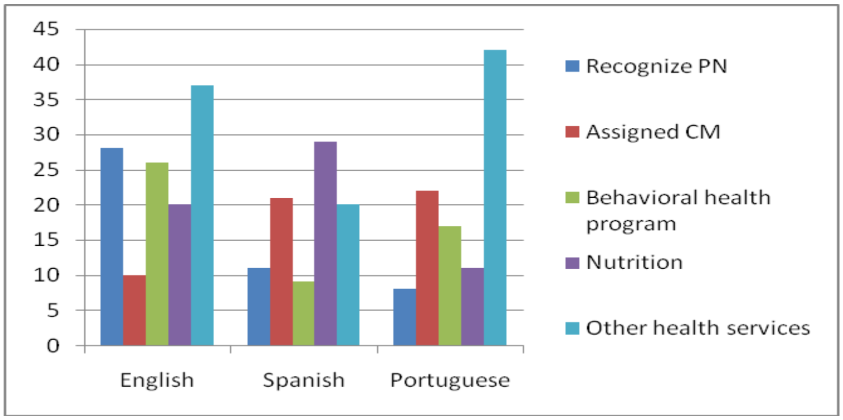
Those born in the U.S. were more likely to recognize the name of a patient navigator than were immigrants, but of those assigned a patient navigator, the more important ethnic identity was to them, the more ways they had been helped by the patient navigator (r=.27, p<.05). Those born in the U.S. were also more likely to have used a behavioral health program and to have used "other" health services than were immigrants (Exhibit 52). There were no differences in having been assigned a case manager between those born in the U.S. and immigrants.

Exhibit 52
Engagement in Health Care by Immigrant Status



Those who spoke English were more likely to recognize the name of a patient navigator than were those who spoke Spanish or Portuguese, but they were less likely to have been assigned a case manager (Exhibit 53). Compared to those who spoke English or Portuguese, Spanish speakers were more likely to have used nutrition/cooking services and less likely to have used behavioral health programs or "other" health services.

Exhibit 53
Engagement in Health Care by Language Preference



Medical Sites

Almost all of the patients surveyed (95%) received all or most of their health care at the site used by DPH to provide Care Coordination services.

Exhibit 54

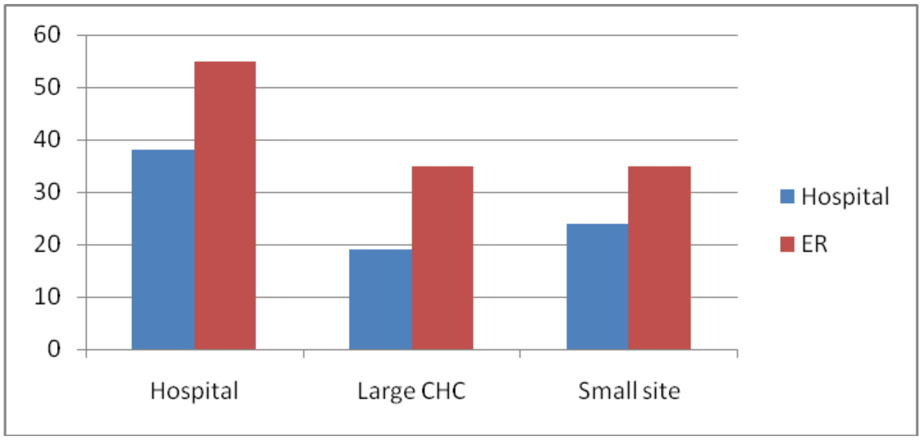
Knowledge of PN, CM by Health Care Site

Site	N	%PN	%CM
BMC	34	24	9
Signature, Brockton	32	19	15
CHA	30	23	14
Tapestry, Northampton	5	40	20
Great Brook	1	0	0
Joseph Smith	75	16	16
MGH Chelsea	13	8	9
VNA	7	14	17
FHC, Worcester	36	11	10
North Shore	25	0	14
CHP, Berkshires	23	44	13
Greater Lawrence	13	46	18
Health First, Fall River	8	38	71
Whittier	45	29	16
CHC, Fitchburg	18	6	0
Cape Cod CHC	18	28	6
Total	383	21%	14%

The type of site where CC patients received care was related to their likelihood of being hospitalized or using the emergency room (Exhibit 55). Patients who received their CC services at a hospital site were much more likely to have been hospitalized or to have used the emergency room in the past year than those who received CC services at a community health center.

Exhibit 55

Hospitalized or ER Use by Site Type



There were few differences in patient satisfaction between the major larger providers. One large center received lower ratings for the overall quality of care, particularly from Hispanics, but its case management services were rated more positively those those provided at other sites. Another large provider received lower overall health care quality ratings from blacks, as did two centers witih respect to whites. One provider outside of Bosotn was rated by black patients as providing particularly good health care.

Summary

Four in every five respondents had received at least one health service in the preceding year, with dental services being the most common and use of emergency services also being frequent. However, most of those who reported a specific health problem had not received a service specifically for that problem. The exceptions were substance abuse and dental problems, for which at least three-quarters reported treatment. Services specifically for the frequently reported health problems of depression/anxiety and hypertension were reported by only 30-40 percent, and rates of treatment for most of the other specific health problems were even lower.

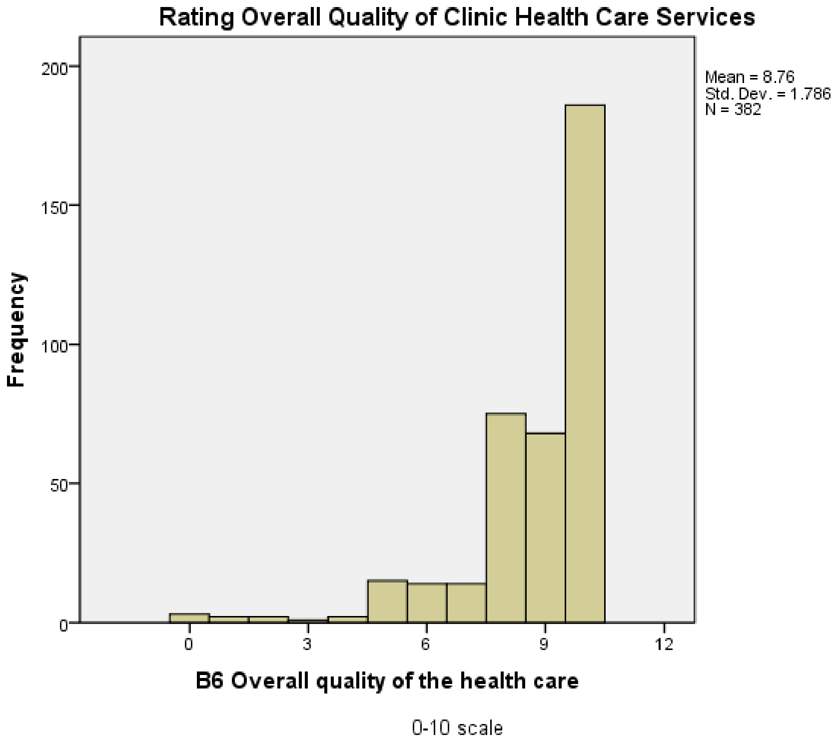
Although incidents of hospitalization and emergency service use were not linked to specific health problems, the differences in rates of hospitalization and ER use between respondents with specific health problems indicates the conditions that drive these most expensive forms of health care. The health problems associated with the highest rates of ER use were CVD, asthma, and substance use, while the rate of hospitalization was elevated for those with CVD and substance abuse.

Most respondents were unaware of having been helped by a patient navigator, even when they were read the names of patient navigators in their clinic. Patients with cancer concerns and diabetes were more likely to be aware of having had a patient navigator and those who were depressed were in more frequent contact with their patient navigator than others. Those who were aware of having had contact with a patient navigator reported a range of services, with help scheduling appointments being the most common form of assistance and transportation assistance being the least. Contact with case managers was also uncommon among the patient sample as a whole, with it most likely to have occurred with patients having had cancer concerns.

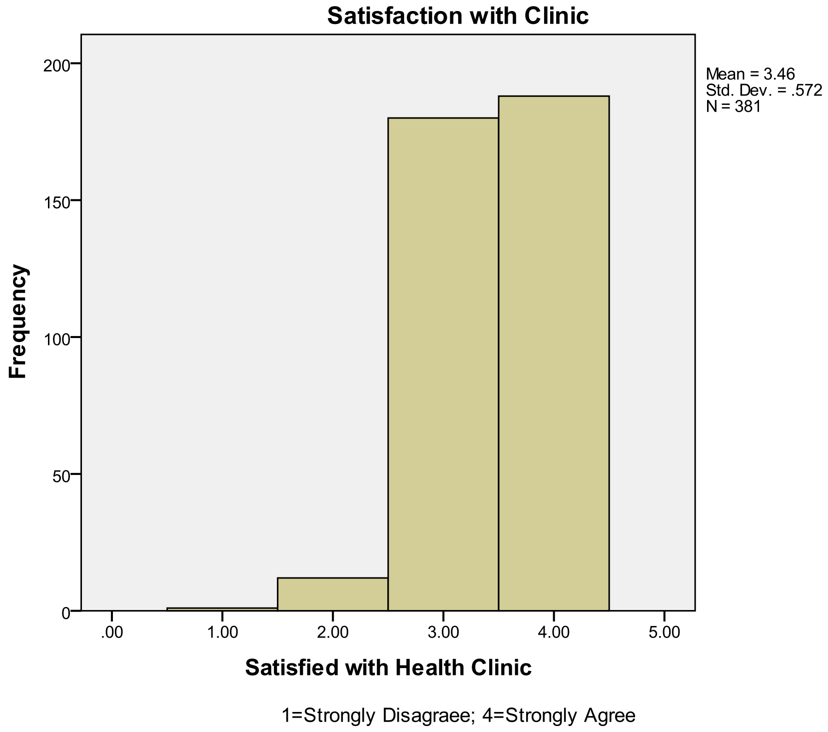
There was some variation in awareness of patient navigation and case management services by ethnicity and its correlates. Hispanics were less likely to recognize the name of a patient navigator, as were immigrants and those who spoke Spanish or Portuguese. However, Spanish and Portuguese speakers were more likely to have been assigned a case manager than English speakers.

Evaluation of Health Care

The phone survey provided considerable evidence of high levels of satisfaction with services. When asked to rate the overall quality of the health care they had received from the health clinic on a scale from 0 to 10, the average (mean) rating was 8.76 and only one in ten gave a rating of 6 or lower.

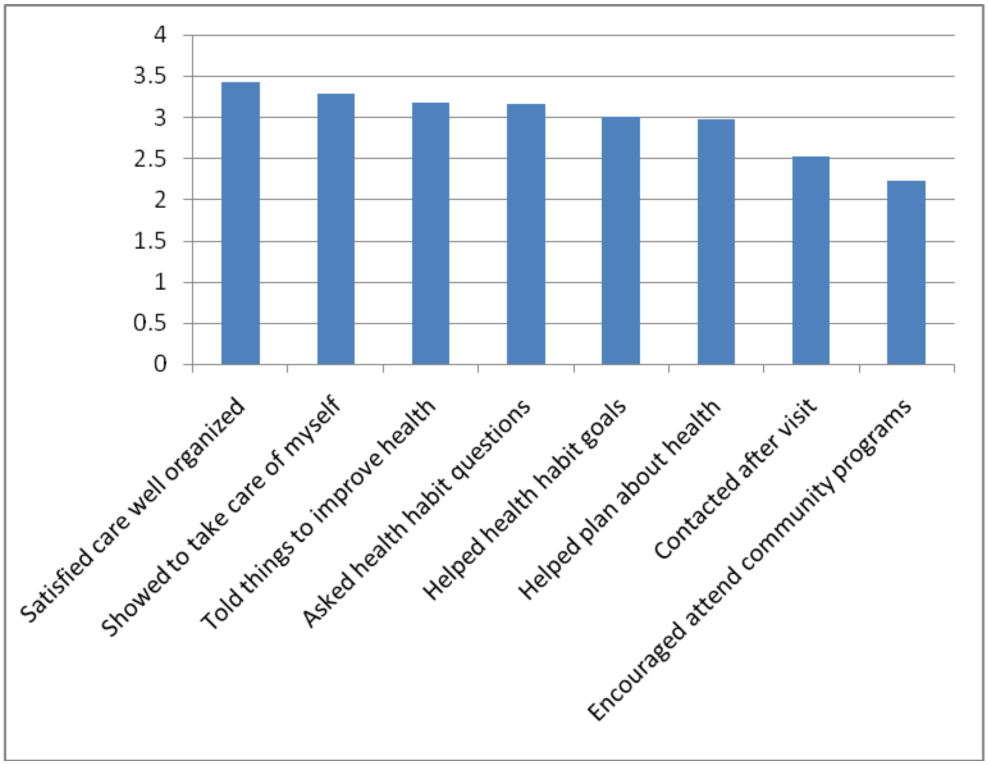


Almost all respondents agreed or strongly agreed that they were satisfied with the clinic overall as well as with its convenience, that they were doing better because of the clinic, and that they would recommend the clinic to a friend.



Ratings of specific aspects of care received at the health clinic in the preceding year were also very positive. On a scale from “none of the time” (1) and “some of the time” (2) to “most of the time” (3) and “all the time” (4), average scores were three or higher for organization of the care, being given advice in various ways, and being asked questions about health habit. The only clinic actions rated somewhat lower, with an average score of 2 (and most respondents indicating “none of the time” or “some of the time”) were about followup: being contacted after a visit to see how things are going and being encouraged to attend programs in the community that could help.

Reactions to Health Care Received in Past Year*

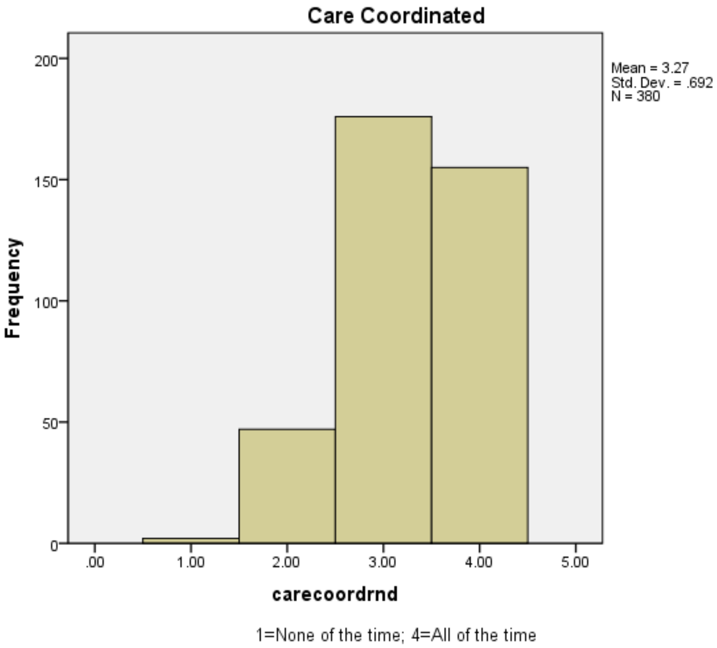


*1=None of the time; 2=Some of time; 3=Most of time; 4=All of the time.

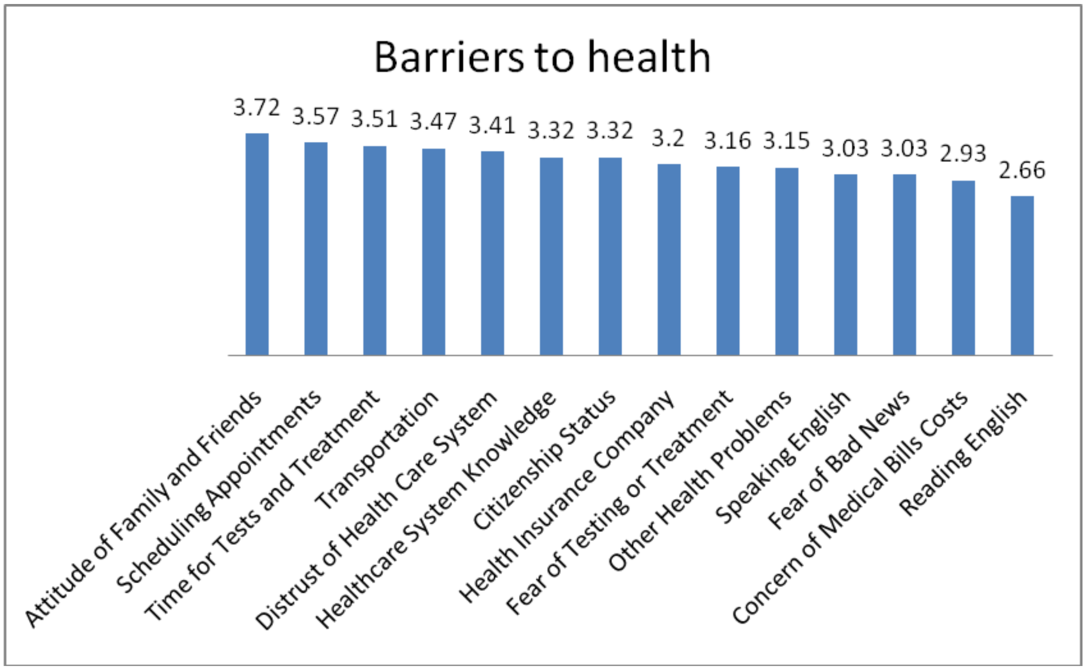
The responses to three questions about care coordination were also very positive, with eight in ten reporting that their care was well coordinated all or most of the time and just two in ten reporting that they were confused about roles of different service providers all or most of the time. Ratings of the frequency with which the respondent's main health care provider communicated with other providers were only slightly less positive, with six in ten reporting this had occurred all or most of the time.

Some of the patients interviewed in person had had some negative experiences at their clinic. The most common problem noted was with inadequate dental coverage and some patients found that copays for physical therapy or for medications were too high. One reported that after her clinic installed a new answering system, she could not reach a person about appointments and her calls were not always returned; however, a patient at another clinic reported that staff had become more attentive to patients over time. There were some very particular experiences that led to dissatisfaction: one patient was disillusioned with a nutritionist who had promised to call and never did, another had not been informed when her PCP—who she liked—left and she was not informed; yet another was not sent her lab results as she had requested.

The one patient interviewed in person who was very dissatisfied with her care rated all the staff at her clinic as irresponsible and found that it took a long time to be seen. She had had doctor's appointments cancelled and then had difficulty rescheduling them, and her child had been given unnecessary vaccinations, and had had personal belongings taken while she was at the clinic. Among those interviewed in person, at least, this seemed to reflect a unique exeprience. However, another experience described by several interviewees was a decision to seek medications or other treatments in their home country, due to the belief that traditional treatments were superior. These experiences were not shared with their health care provider at the clinic.

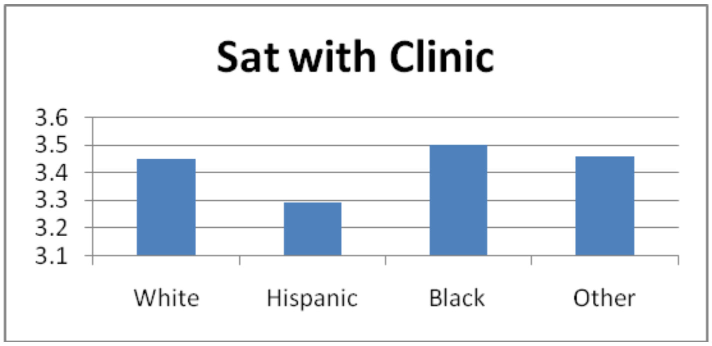


There were more concerns expressed in the phone survey in relation to potential barriers to receiving health care. Among the respondents for whom English was not their primary language, reading English was rated as a major problem by one-quarter and communicating with health care staff in English was also rated as a common problem. For the sample as a whole, the most commonly experienced barriers were concerns about medical bills and fear of receiving bad news. Fear or anxiety about testing or treatment, dealing with health insurance, and other health problems were relatively common barriers. Among those who had immigrated to the United States within the previous 15 years, one-third reported their citizen or immigration status was a major or moderate problem in getting health care.

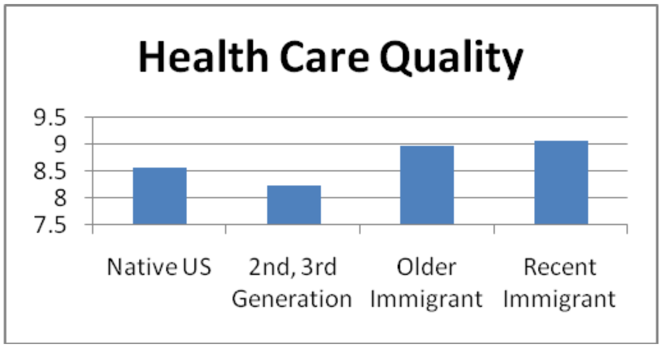


Patients also answered a direct question about health care costs. Twenty percent of respondents said they had been unable to receive some needed health care services because of the cost. This percentage rose to 34 among those who had a case manager (an indicator of a more serious health problem). There was no difference in reports of health care cost problems between those who recalled a patient navigator and those who did not.

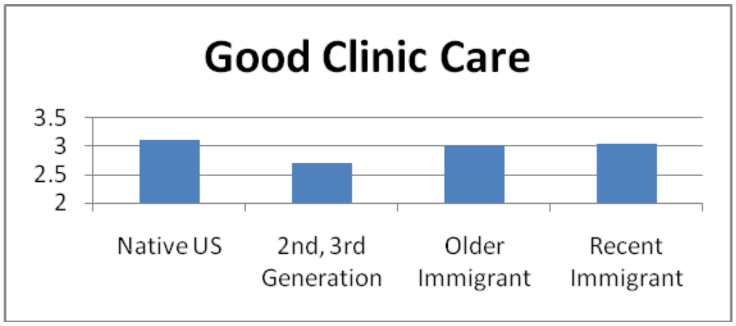
Satisfaction with health care services varied with ethnicity and related indicators. Hispanics were less satisfied with their health care clinic than others. Among patients interviewed in-person, those who spoke Spanish were generally pleased with their ability to get an interpreter or to speak to a provider in their native language.



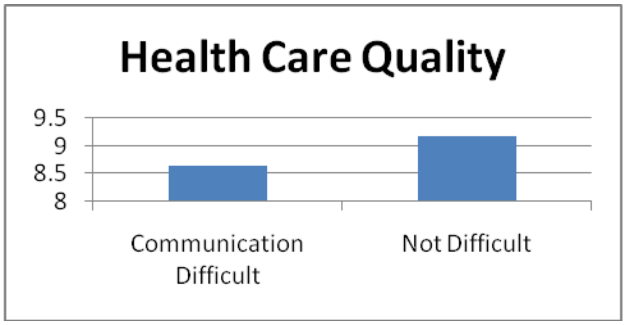
Those from second or third generation immigrant families rated lower than others the overall quality of the health care services they had received from their health clinic.



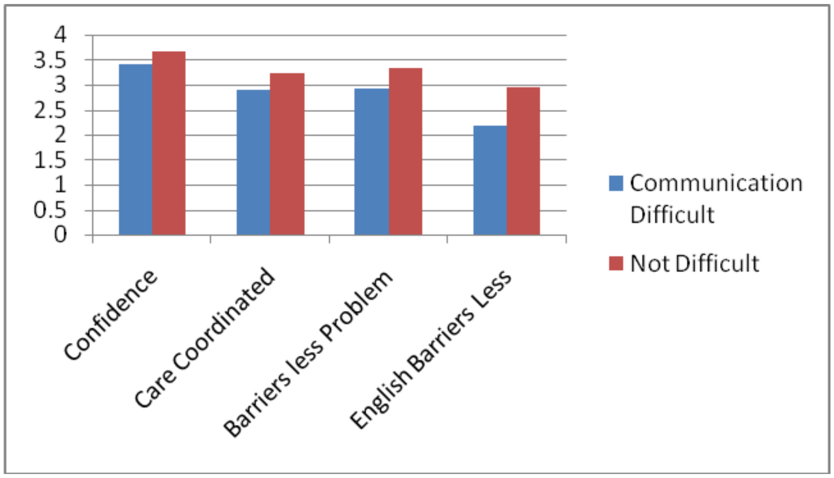
They also their satisfaction with the specific services they had received there.



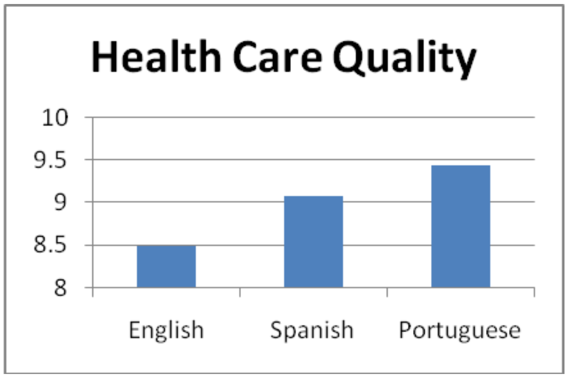
Difficulties with communication lowered ratings of health care quality.



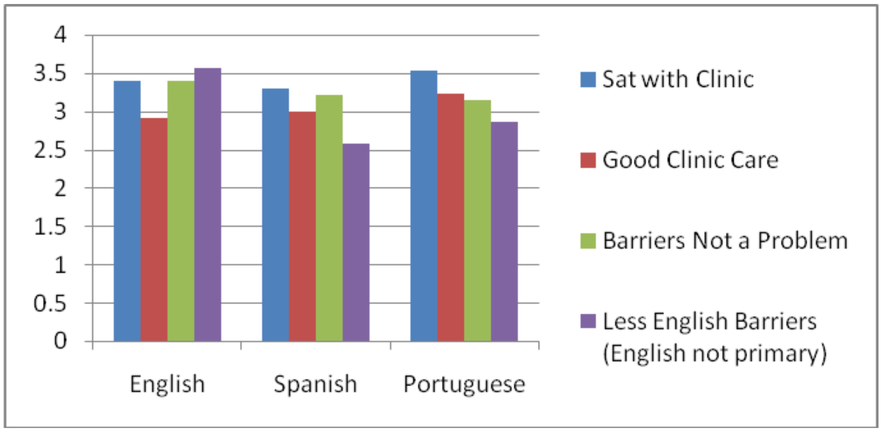
Communication difficulties also undermined satisfaction with specific health care services and they raised perceptions of barriers to receiving health care services.



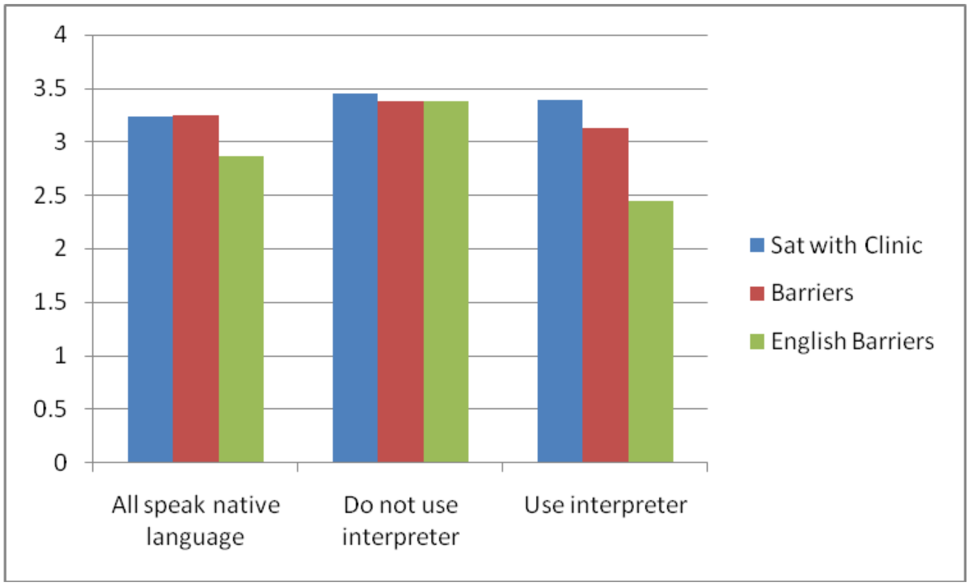
In spite of the problems posed by communication difficulties, those interviewed in Spanish or Portuguese rated their health care as of higher quality compared to those interviewed in English.



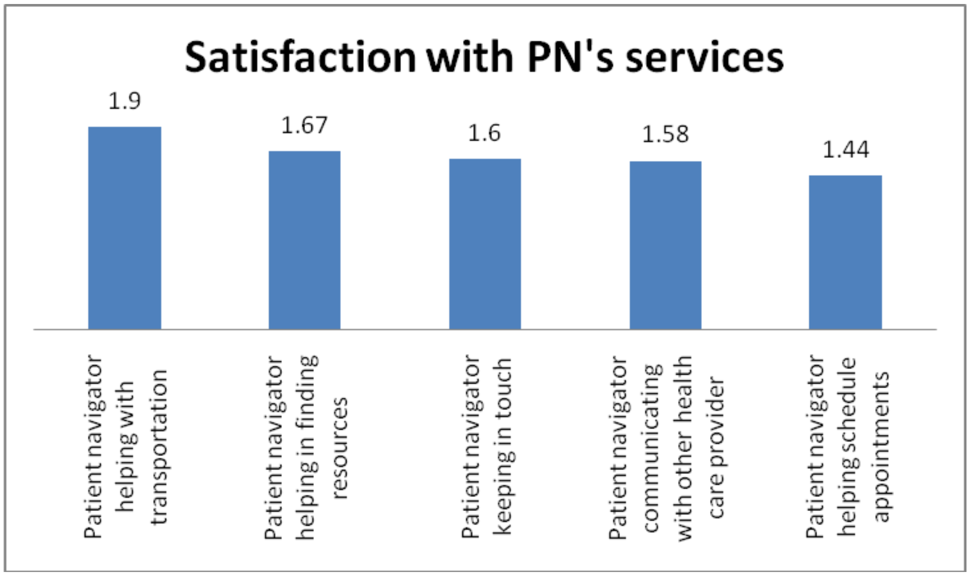
Portuguese speakers were also more satisfied with the care they had received from their health care clinic, but both Spanish and Portuguese speakers indicated more barriers to health care due to language problems.



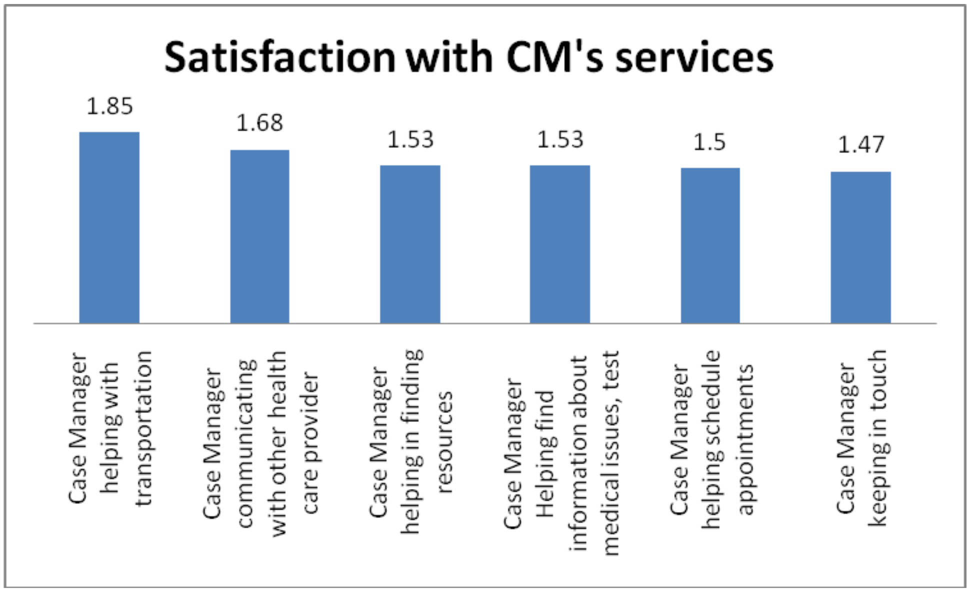
More specifically, it was those who had to use an interpreter at least some of the time when they received health care services who rated language problems as more of a barrier to their health care.



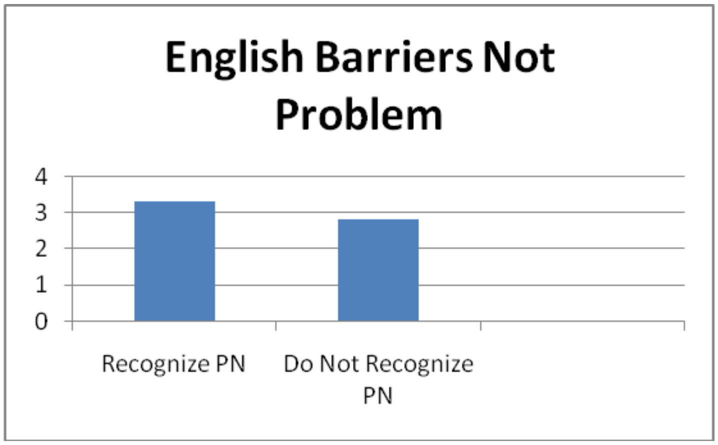
Those who were aware they had a patient navigator were asked to rate their satisfaction with specific patient navigation services, ranging from help with transportation to scheduling appointments. These same questions were asked of those who were not aware of having a patient navigator, but in reference to help they received at their health center. There were no differences between these two groups in their satisfaction with these services. They were mostly satisfied or very satisfied with help provided by their patient navigator and/or at their health clinic. Help with scheduling appointments elicited the highest level of satisfaction and help with transportation elicited the least satisfaction. As in the total phone survey sample, only a few who were interviewed in person were aware of having a patient navigator, but those who did know their patient navigator were very satisfied with the services the navigator had provided.



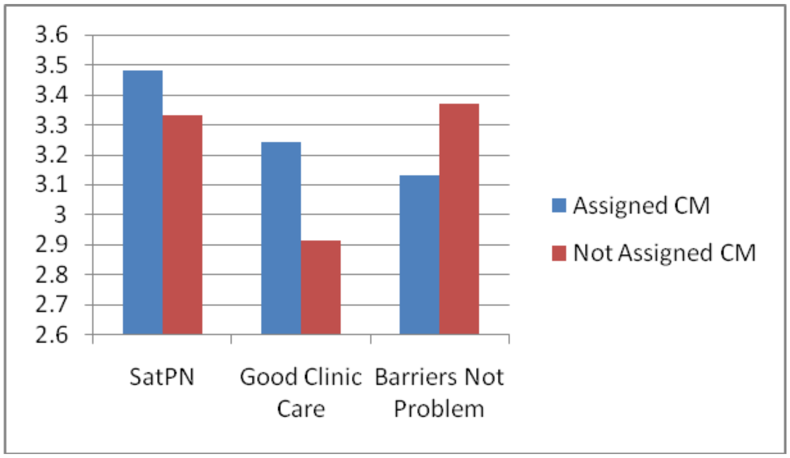
Those who had received case management services were mostly satisfied or very satisfied with those services, with help with transportation and communicating with other health care providers eliciting somewhat lower levels of satisfaction than other services.



Those who were aware of having been assigned a patient navigator varied little in satisfaction with their health care compared to those who were not aware of a patient navigator. The only difference in satisfaction was that among those for whom English was not their primary language, English barriers were seen as more of a problem for those who were not aware of having a patient navigator.



Those who had a case manager at the health clinic were more satisfied with their patient navigator, they rated the health care clinic as providing better services, but they also reported more barriers to receiving health care than those who did not seem to have a case manager.



The 30 (28) Care Coordination patients who were interviewed in-person provided more more insight into these high levels of satisfaction. These patients were similar in every measured respect to the other patients interviewed by phone and with just one exception they were very satisfied with their experiences at their CC health clinic. They described staff as very helpful and efficient, friendly, not rushed, and in general providing care that is “really good,” “fast,” "excellent," or "perfect." Experiences that were often mentioned as important bases for such satisfaction were reciving reminders about appointments—both letters and phone calls (even when those calls were automated), not being rushed through appointments by doctors or other staff, and feeling that the care was coordinated.

Multiple regression analyses facilitate identification of effects of the different predictors of health care satisaction that are independent of each other. Across four different measures of health care satisfaction (overall service quality, satisfaction with the clinic, satisfaction with specific health care services, and satisfaction with care coordination), those who spoke Portuguese in the interview and those who rated their own health more positively tended to be more satisfied, while those with more education and those who perceived more health barriers tended to be less satisfied.

Among Hispanics in particular, age was associated with higher satisfaction ratings and awareness of having a patient navigator was associated with higher ratings of health care service quality. It was only among white respondents that awareness of having a patient navigator was associated with greater satisfaction with the clinic, higher ratings of specific health care services, and perceptions of more care coordination.

Summary

Care Coordination patients were very satisfied with their health care experiences at the clinics from which they received their health care and rated specific services received and the apparent level of care coordination highly. Ratings of followup, of help with transportation, and of apparent communication with other health providers were somewhat lower, but still largely positive. In spite of these high ratings, respondents reported some barriers as particularly problematic, including concerns about costs and fear of bad news. Those who were Hispanic, first generation immigrants, and who had difficulties communicating in English were somewhat less satisfied with some aspects of their health care experience, but those who were interviewed in Spanish or Portuguese tended to be more satisfied. Recognition of having a patient navigator or case manager was associated positively with only a few aspects of service satisfaction. One key difference was that among those whose primary language was not English, those who recognized a patient navigator reported fewer communication problems. In addition, those assigned a case manager were also more satisfied that staff kept in touch about their health needs.

Conclusions

The Care Coordination Program evaluation allows insights about implementation of the program and the type of patients it serves, about the value of patient navigation for the program's patients, and about the role of program case managers. These conclusions present insights in each of these areas, but all of them can be best understood in relation to the Women's Health Network, the predecessor program that was described after a previous evaluation (Schutt and Fawcett, 2005), and in light of the recommendations of the Expert Panel that reviewed the earlier evaluation findings and other, related research (Schutt, 2005).

The Department of Public Health sought through the Care Coordination Program to replace the cancer-specific focus of the Women's Health Network and the Men's Health Partnership with a program that took a holistic health approach to providing prevention-oriented services focused on chronic illness and that used patient navigators to overcome cultural and linguistic barriers to effective delivery of those services. This evaluation reveals that substantial progress has been made toward achieving these goals, even while there are ways in which the program can be improved.

Program implementation had occurred at different rates and had succeeded to varying degrees at the 17 different program delivery sites. Where the Care Coordination approach had been most fully adopted, patient navigators, case managers, and program directors met together regularly with others in the health care system and sought actively to engage patients in prevention activities. Patient navigators in these sites, and to some extent wherever they worked, improved engagement and continuity of care with program patients and overcome some of the cultural and linguistic barriers to effective delivery of health care services. Most patient navigators were bilingual and came from less educated backgrounds and were less likely to be married than the program's nurse case managers.

Characteristics of the program's patients make it clear just how important cultural fluency and language skils are for engaging effectively with patients. Care Coordination patients are mostly first, second, and third generation immigrants, w ith half having been born outside of the United States and half of these having arrived in the U.S. within the preceding 15 years. Many of the first generationa immigrants preferred to converse in their native language. When these patients had to rely on interpreters to communicate with their health care providers, which was the case for many Portuguese speakers and others whose native language was neither English nor Spanish, their communications about health care were less satisfying. Patients who were immigrants also tended to be less educated, to have more dependent children, and to report poorer health than those born in the U.s.

The most common health needs reported by patients were hypertension, depression, and dental problems. Although most patients had received some health services related to these problems, many had not. Among immigrants as a whole, there were fewer reports of depression, asthma, smoking, and substance abuse, while the prevalence of other health problems varied in relation to specific language groups, ethnicity, and length of time in the U.S. Rates of hospitalization and emergency room use were highest among those who reported CVD and substance abuse problems, and emergency room use was also elevated among those who reported that they had asthma. Overall, hospital and ER use were more common among patients using hospital-based Care Coordination providers.

Patient navigators found their work with Care Coordination patients to be satisfying, but reported challenges in delivering services for psychosocial needs, including mental health needs, in dealing with cultural beliefs and problems with literacy, and in assisting with employment and transportation needs. Patient navigators tended to feel they were more able to respond to these needs than were case managers, and were more satisfied with their jobs overall than were case managers. Nevertheless, both patient navigators and case managers reported a need for more training about their jobs and for more in-person contact with their patients—many of whom they only engaged with over the phone.

On their part, patients reported high levels of satisfaction with the health care they received from their health center, but they reported some barriers as particularly problematic, including concerns about costs and fear of bad news, and they were less satisfied with followup about their health, with transportation, and with communication involving other health providers. Many, particularly Hispanic patients, did not know their patient navigator, but those patients whose primary language was not English and who did know their patient navigator reported fewer communication problems. Hispanic patients, first generation immigrants, and those who had difficulties communicating in English were somewhat less satisfied with some aspects of their health care experience, but those who were interviewed in Spanish or Portuguese tended to be more satisfied.

Overall, the Care Coordination Program has helped to lower health care barriers for the most vulnerable and disengaged patients in Massachusetts and it has highlighted the importance of a holistic approach to their health needs. Patient navigators have established their value in achieving these goals, but there is still much room for improvement in the definition of their role in some health centers. Engagement of nurse case managers in the Care Coordination Program has been less effective in many health centers, as the program focus has shifted from cancer testing and followup to care for chronic conditions.

Several changes should help to improve the program's effectiveness:

- Ensure some time for patient navigators to visit patients in the community, to meet with patients in person, and/or to attend health fairs and other community events.
- Expect a team approach to program delivery at each center, with regular team meetings and case reviews.
- Expect center meetings and regular email blasts to publicize the Care Coordination program and ensure understanding by all staff of the roles of patient navigators and case managers.
- Provide training for case managers focused specifically on Care Coordination responsibilities and roles.
- Include some joint training sessions with patient navigators, risk reduction educators, and case managers.
- Enhance transportation assistance through program linkages and funding.

- Improve followup after patient visits and to encourage patient participation in relevant community programs.
- Add more forms of language assistance for Portuguese speakers and encourage recruitment of more Portuguese-speaking staff.
- Provide options within the program for dental care.
- Use a more proactive approach to engage patients with unmet health needs in the specific health services they require.
- Enhance the availability of mental health services for those with depression.
- Develop guidelines and encourage coordination of on-the-job training for program staff.
- Schedule regular meetings for staff exchange about best practices and case histories.
- Develop strategies that give case managers greater time for their Care Coordiantion work.
- Create a greater sense of program engagement by case managers through team meetings, focused training, and opportunities to share responsibilities for patients.
- Maintain a record of all contacts of patients with patient navigators and case managers as part of patients’ medical records.
- Add chronic disease indicators and related services as required fields in the program database.

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