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REVIEW

Implementation of evidence-based patient navigation programs

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ABSTRACT

Background: Patient navigation refers to a direct patient care role that links patients with clinical providers and their support system and provides individualized support during cancer care, ensuring that patients have access to the knowledge and resources necessary to complete recommended treatment. While most reports have studied the role of patient navigators during the cancer screening or diagnostic process, emerging evidence indicates the benefits of patient navigation during active cancer treatment.

Discussion: Reports in the literature are conflicting on the impact of patient navigation during cancer care and on the benefits to timely or quality care in all populations. Recent sub-analyses of the Patient Navigation Research Program data demonstrated specifically the benefits of targeting patient navigation to the most vulnerable populations, including those with low educational attainment, low income and unstable housing, less social support, multiple comorbidities, and minority race/ethnicity.

Conclusion: The implications of the Patient Navigation Research Program are that this resource is best utilized when directed to support the care of patients at locations with known challenges to timely care and for specific patients with risk factors for delays in care, including comorbidities, low educational attainment and low income. Implementation of patient navigation programs requires the following processes: needs assessment, selection of a navigator to meet the community and care needs, supervision and integration of the navigator into clinical processes, and systems support to facilitate the identification and tracking of those patients requiring patient navigation. There is a need for ongoing research on methods to fund and sustain patient navigation programs.

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Disparities in cancer outcomes by social variables including income, education and race/ethnicity persist in the US and elsewhere [1,2]. As cancer care becomes more effective, the process of care for many cancers has also become much more complex, with multi-stage evaluation methods for diagnosis of both screening abnormalities and symptoms, and multi-modality treatment regimens. Data consistently show that for cancers where treatment has survival benefit, disparity gaps in outcomes persist and may be widening [3,4]. The social determinants of health [5] – factors such as low education attainment and low health literacy, income and housing instability, personal and family safety – have a major impact on the ability to complete recommended cancer screening, diagnostic care and treatment in a timely fashion.

Among the numerous clinical interventions that have been developed to address these barriers to clinical care, patient navigation has specifically shown promise and is now incorporated into some guidelines for clinical care [6]. Patient navigation refers to a direct patient care role that links patients with clinical providers and their support systems and provides individualized support during cancer care, ensuring that patients have access to the knowledge and resources necessary to complete recommended treatment. Patient navigators are commonly individuals with non-clinical training, who provide linkages between the patients, their families and communities, and their clinical providers through identifying the barriers that patients perceive in receiving recommended cancer care and coordinating access to resources to address these barriers.

Patient navigation in cancer screening and diagnostic evaluation

Several review articles and large clinical trials have focused on the benefits of patient navigation for cancer screening and diagnostic evaluation following abnormal screening [7–9]. Most of these studies have found modest overall benefits of patient navigation in these areas. Most of these studies have focused on vulnerable patients – defined as economically disadvantaged, under- or uninsured, or from racial and ethnic minority groups – whereas others have focused on all patients in locations of care that traditionally provide services to these populations. Although most studies have focused on breast, cervical and colorectal cancer screening and diagnosis, fewer studies have included lung and other cancer sites. Outcome metrics have focused on proportions of patients who undergo screening and the time to completion of diagnostic evaluation, with less data on patient satisfaction with the care process.

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Patient navigation in cancer care

The current literature on patient navigation in active management of patients with cancer has demonstrated mixed findings on improving timeliness or completion of care, with little data on either quality of care or patient experience with navigation [8,10]. Several studies have shown minimal benefit in the cancer care setting. A review by Krok-Schoen and Paskett [8] identified eight studies in women-specific cancers, with some showing improvements in receipt of guideline-specific care, but fewer demonstrating improvements in patient-reported outcomes including satisfaction with care and quality of life scores. Another review article by Baik [10] and colleagues identified 13 studies in cancer management and reported mixed results on the benefits of navigation. Specific studies without benefit include Bickell [11] and colleagues, who showed no benefit in receipt of adjuvant breast cancer therapy in a randomized control trial at eight New York hospitals. Of interest, this study showed no benefit in patient satisfaction with the navigator experience and, by six months, also demonstrated a lack of recall about the support the navigator provided. This suggests that, during cancer care, patients may not always recall all the supports and care provided, especially early in the treatment of their disease [12]. Weber [13] also found no benefit in treatment adherence, but did find some benefit in post-treatment monitoring. Studies by Haideri [14], Ell [15] and Koh [16] also showed minimal to no benefit on timeliness to cancer treatment. Other studies, however, have shown benefit. Ramirez and colleagues [17] in six city study and Lobb [18] in a multisite program in one state both found a benefit in time to initiation of treatment. Studies by both Castaldi and colleagues [19], and Raj and colleagues found a benefit in completion of guideline recommended treatment. The Patient Navigation Research Program, the largest study to date of patient navigation located at nine sites across the US showed benefits in cancer care, with a greater proportion of patients initiating cancer care in a timely fashion [20], with the benefits focused on those who had not initiated cancer care within 90 days of diagnosis. This study documented a greater adherence to guideline recommended care among the navigation arm of the study [21].

Focusing patient navigation on at-risk populations

Although the data on the benefits for patient navigation in general have been modest, the data that focuses on communities-at-risk demonstrate a much greater impact of patient navigation. The metraregression analysis of the overall Patient Navigation Research Program demonstrated that navigation had the greatest benefit in patient populations with the greatest needs and the lowest rates of diagnostic and treatment timeliness [20]. The same trial also demonstrated that there were specific groups of patients who had the greatest benefit of patient navigation. Patients who reported a greater number of barriers to care [22], and specifically patients with social service barriers [23] (those considered the social determinants of health) including insurance, income, education and family stability, and safety had the greatest benefits of navigation. Subgroup analyses indicated that patient navigation mitigated disparities in timeliness outcomes for those with low income, low educational attainment and housing instability [24]. The greatest benefits of navigation in the trial were among the African American patients who had the poorest outcomes in the control group [25]. This trial found patients with multiple comorbidities had the longest delays in care, possibly due to the additional care coordination necessary to manage their chronic diseases in the context of cancer treatment. This group preferentially benefited from patient navigation compared with patients in the control arm [26].

Implementation of patient navigation programs

Given the findings of: (1) increased disparities in cancer outcomes as cancer care becomes more complex; (2) the increased understanding of the impact of the social determinants of health on cancer outcomes; and (3) data supporting a modest impact of patient navigation overall, with potential increased benefits with targeted use, there are implications for how to utilize this data for the implementation of patient navigation programs. Several components of a navigator program are critical in order for the implementation to be successful: (1) needs assessment to identify the target subpopulations in need of services; (2) identification of the skill set needed for a navigator based upon the needs assessment; (3) supervision and integration of the navigator into the clinical care program; and (4) systems support for identification of patients in need of services, and tracking to ensure care is delivered.

One of the major challenges to implementation of patient navigation programs is the variability in the navigation programs currently assessed within the medical literature. Although there are common themes among the programs and specific tasks that most programs hold in common, programs have substantial variability in who serves as a navigator, what tasks the navigator performs, and what specific outcomes are desired of the navigation program. Recent literature [27] has attempted to define the common elements of patient navigation, which align with the four components described below.

Needs assessment

The current literature suggests that patient navigation is most effective for those patients with barriers to care, and these barriers can be identified through an assessment of the social determinants of health. The Commission on Cancer [6] recommends that cancer care programs assess their populations to determine which patients require navigation before the implementation of a program. A needs assessment can include a review of metrics of quality cancer care that have already collected to identify subgroups with poor outcomes on processes measures, including time to initiating care, time to completion of certain aspects of care, or receipt of guideline recommended care. Many systems already collect demographic information that can be used to assess population

subgroups, including age, race/ethnicity, primary language or need for interpreter services, and the presence of social supports including spouse or other adult caregivers. Current collected data can also provide a proxy for income or educational attainment, including current or prior occupation, location of residence (e.g. in the US, use of zip codes), and in the US, type of insurance coverage. Evaluation of this existing data for subgroups with poorer outcomes can be supplemented with qualitative interviews with members of the clinical care team that have direct patient contact (physicians, nurses, appointment coordinators) to elicit their perspectives on which patients have the greatest barriers to care. Qualitative interviews with patients with prior delays can often identify their perspective on the process of cancer care and their understanding of the barriers and facilitators to completing their course of care.

Once the needs assessment is complete, the specific subpopulations in greatest need of navigation can be identified for targeting of this service. Many of the factors may be identifiable in data already available within the registration database to distinguish specific target groups. New patient intake forms can be modified to add questions not already collected in order to assess who would benefit most from navigation. Some programs have specific algorithms for identifying potential at-risk patients, with the option of providers referring additional patients whom they believe would benefit from this service.

Skill set of the navigator

The needs assessment is critical to defining the skill set needed to provide the navigation services. The specific needs of the target population will dictate the greatest service needs and the skill set of the navigator should align with these. For example, programs with a rural population may find that navigators focus on finding transportation solutions, including some programs with navigators serving as drivers. Urban programs may focus their transportation issues on finding vouchers for low cost transportation when public transportation options do not meet with the patient's physical limitations during cancer care. Navigation services for immigrant communities benefit from navigators with the necessary language and cultural competence [28]. Most patient navigation programs are focused on non-clinical or lay navigators, and have the navigators focus on non-clinical aspects, including coordination of scheduling, transportation issues, interpreter services, and identifying child and elder care needs [29]. This allows the nurses and physicians to focus on the clinical aspects of care. In practice, many programs have found that navigators are faced with clinical issues that overlap with their logistic needs. In addressing fear of cancer, navigators may be asked to clarify physician or nursing instructions, or identify gaps in patient knowledge. For patients with multiple medical comorbidities, substance abuse issues or mental health disorders, the navigator may be faced with additional clinical challenges. Some programs have developed hybrid navigator programs [29], with navigators with nursing or social work background assigned to patients with these multiple comorbid conditions.

In addition to the training background of the navigator, programs have discussed personal characteristics that distinguish the best navigators [29]. Although some programs seek cancer survivors or those with previous experience caring for cancer patients, at least one study suggests that these experiences are not essential to providing the necessary empathetic and logistic care that is needed for patient navigation [30]. Programs have found that individuals with excellent problem solving abilities who are comfortable dealing with a diversity of patients are suited to the navigation roles, including individuals with past work expertise within the healthcare field or those with personal experience and language skills to effectively communicate with the target population.

Supervision and integration of the navigator

In order for navigators to be effective, navigators require champions to assist with their integration into the health care system and supervisors to define and monitor the tasks and activities that the navigators provide, maintaining an appropriate scope of work that does not extend into clinical care. As the patient navigator is often a new role within the healthcare system, there is an initial need for a champion to serve to support the navigators as they integrate their services within the care team. This requires careful delineation to ensure navigators are not taking on the tasks better allocated to either clinicians or administrative support already present within the care team, and ensuring that clinical systems develop so that navigators and clinicians are aware of and can coordinate their work.

There are two major components to the supervision of patient navigators, which can be assumed by a single person or two people. Navigators require a clinical supervisor familiar with cancer care, who can review cases and discuss issues that arise. This supervision ensures that navigators stay within their scope of work, and that navigators receive necessary training for their tasks and activities. An administrative supervisor addresses issues such as hiring and training, caseload management, and documentation to ensure that the clinical care team is aware of navigation activities. The administrative navigator will make clear the process and outcome goals of navigation and, ideally, have an easy means of tracking their progress. For example, if a process goal is contacting or meeting a patient within a set time point after their initial oncology visit, the supervisor would be able to monitor this metric on a regular basis and review this with the navigator.

Caseload for navigation has not been clearly defined in the literature, with navigation for cancer care likely requiring a smaller caseload than for diagnostic or screening services. Some initial discussions have recommended active caseloads between 20 and 50 cases, depending on patient needs and frequency of contact and services [29].

Systems support

Institutional infrastructure support, including information system support, is critical to ensure the success of a navigator program.

Systems are needed that can readily identify the patients classified as high risk for whom navigation is indicated. The system should have seamless means for navigators to document their activities and share this information with other clinicians providing that patient's care, as well as a method for the providers to communicate with navigators if there are special needs. In addition to such input on the individual patient level, the ability to monitor active cases is needed to proactively identify patients who have missed appointments or other milestones, in order for the navigator to take action to reengage these patients into care. Finally, the system should allow for clear documentation when navigation has reached its conclusion and the navigator can end the case.

Areas for future research

There are a number of questions for which additional research could assist in implementation of navigation programs. The most critical are how and when to utilize clinically trained personnel, including those with backgrounds in nursing and social work, to support lay navigators when navigating patients during active cancer treatment. The logistic needs of transportation, appointment schedule coordination and language interpretation can overlap with issues such as health literacy, understanding of treatment goals and side effects, and fear of the diagnosis and prognosis. These can be compounded in patients with medical comorbidities and psychiatric or substance use disorders. A clearer understanding of how to coordinate clinical and non-clinical support needs would be useful for delineating specifically how to develop navigation during cancer care. Dissemination and implementation research is needed to compare models of patient navigation with lay navigators, with navigators from social work or nursing to understand which clinical skills are needed in different clinical situations, especially for the most socially complex patients. A second area of major research is identifying how to assess caseload for a navigator. Related to the issue of roles for lay navigators for complex patients, an understanding of the optimal caseload is needed in order to ensure patients receive the support to complete guideline recommended care.

There is a need for implementation research to address the funding and long-term sustainability of patient navigation programs. Most programs have paid navigators, given the need for integration of the navigator's work into the healthcare system, and their access to confidential information. Volunteer-based programs alone may not be sustainable, as there are ongoing expenses including program management, and workforce development and supervision. Currently in the US, there are few insurance-based resources to support patient navigation, and either institutional funds, or philanthropy through individuals or foundations routinely funds these programs. Implementation research should include qualitative interviews with hospital administrators to understand their metrics for funding such programs. Additional implementation research which demonstrates not only the costs to the healthcare systems, but the potential savings should be included, in terms of increased practice efficiency due to fewer missed appointments, and better utilization of clinicians efforts away from non-clinical tasks. One potential payment strategy for patient navigation is through incentives for quality of care. This method is already utilized for primary care 'patient center medical home' models, which provides resources for a practice to hire a care coordinator, in order that population metrics of quality care are met [31]. If oncology care moves away from fee-for-service model and towards bundled payments or incentive payments for guideline-based care, this would provide practices the flexibility to use dollars towards patient navigation.

Conclusion

Although a number of unresolved questions regarding patient navigation remain, the current literature provides guidance on the development and management of programs to support patients during active cancer treatment. As we consider personalized medicine in terms of the genetic determinants of specific cancers, we should also consider the personalized supports necessary to overcome the social determinants of health in order to achieve the best cancer outcomes for all.

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