

Original Article

Physicians' Perspectives on and Experiences with Breast Cancer Patient Involvement in Health Care

Eiman El-Sayed¹, Nabil Dowidar¹, Azza A. Mehanna^{2*}

¹ Health Governance Unit, Medical Research Institute, Alexandria University, Egypt

² Health Administration and Behavioral Sciences Department, High Institute of Public Health, Alexandria University, Egypt

Abstract

Background: The traditional paternalistic model of medicine has been evolving toward a participatory model in which patients and clinicians work in partnership toward the common goal of improved health.

Objective(s): This study aims to explore physicians' perspectives on and experiences with breast cancer patient involvement in cancer care.

Methods: A cross-sectional descriptive study was conducted on 38 physicians in surgery and oncology outpatient clinics and surgery inpatient wards at the Medical Research Institute Hospital-Alexandria University and Ayadi El-Mostakbal Cancer Care Center-Alexandria, Egypt. A self-administered questionnaire was used to collect data on physicians' perspectives on patient involvement.

Results: Only 8% of the physicians indicated high involvement of their patients. "Receiving enough information" and "knowing the benefits and risks of treatment" were the most frequently reported areas of patient involvement (57.9%). The doctors ranked "low education and low social level" and "lack of awareness" as the most important patient-related barriers and "complex routines" and "unavailability of awareness-raising programs" as the highest-ranked organization-related barriers.

Conclusion: Findings of the present study revealed that physicians lack a supportive system to promote patient involvement and that patient involvement needs to be enhanced especially in the public sector.

Keywords: Patient involvement; Physicians; Breast cancer; Egypt

Available on line at:

www.jhiph.alexu.edu.eg

Print ISSN: 2357-0601

Online ISSN: 2357-061X

CC BY-SA 4.0

✉Correspondence:

Email:

hph.Amehanna@alexu.edu.eg

Suggested Citations: El-Sayed E, Dowidar N, Mehanna AA. Physicians' Perspectives on and Experiences with Breast Cancer Patient Involvement in Health Care. JHIPH. 2020;50(3):165-171.

INTRODUCTION

Patient involvement (PI) is a vast and complex subject⁽¹⁾ with many functional definitions. For the present study, we used the following definition: involving patients in decisions and care processes throughout their hospitalization.⁽²⁾ However, involvement is not synonymous with compliance, which refers to obeying directives from health care providers.⁽³⁾ Involvement is a key element and even a necessary condition for patient-centered care.⁽⁴⁾ Multiple researchers have investigated the benefits of PI, which include increased patient satisfaction and trust, higher quality of life, reduced anxiety, better understanding of personal requirements, more positive communication⁽⁵⁾ and increased patient activation and empowerment.⁽⁶⁾ According to the multidimensional model of patient

engagement proposed by Carman et al.⁽⁴⁾, involvement occurs on multiple levels: at the direct care level, patients share perspectives on prevention, diagnosis, and treatment; at the organization and governance level, patients partner with organization leaders, front-line managers, and clinicians to plan, deliver, and evaluate care; and at the policy-making level, the health care system at large is oriented around patients' perspectives.⁽⁴⁾ Under Carman et al.'s multidimensional model, the influences on PI are divided into patient-, organization-, and society-related factors, which refer, respectively, to patients' knowledge, attitudes, and beliefs about their roles; organization policies and practices that promote engagement; and social norms and mechanisms by which patients can provide input and help shape public policy.

Egyptian hospital accreditation standards state that "Patient and family (as appropriate) are involved in all care

and treatment decisions".⁽⁷⁾ Physicians are mandated to offer treatment choices to breast cancer patients⁽⁸⁾, and surgery is usually the first treatment offered; the decision for surgical treatment should be an interplay between patients, their providers, and their family members.⁽⁹⁾

Cancer patients feel anxious and fearful about the prospect of chemotherapy and radiotherapy⁽¹⁰⁾, and breast cancer patients require not only detailed preparatory information to cope with treatment and the resulting self-care demands⁽¹¹⁾ but also psychological and emotional support.^(12, 13)

There are few studies on PI in health care including both patients' and physicians' acceptance of this emerging approach.⁽¹⁴⁾

Hence, the aim of the present study was to explore physicians' perspectives on and experiences with PI in breast cancer care and the barriers to PI in Alexandria.

METHODS

Study setting and design

We conducted a cross-sectional descriptive study at the surgery and oncology outpatient clinics and surgery inpatient wards of the Medical Research Institute Hospital affiliated with Alexandria University and at Ayadi El-Mostakbal Cancer Care Center (Ayadi El-Mostakbal Charity Foundation), both in Alexandria, Egypt.

Study population and sampling

All surgery and oncology physicians (38 physicians, 17 oncologists and 21 surgeons) who were working with breast cancer patients and agreed to participate in the study were included in the study sample. Physicians who were unable to complete the questionnaire due to their limited time were excluded from the study.

Data collection tools and steps

We constructed a structured self-administered questionnaire to collect the following data:

1. physicians' characteristics including specialty, years of experience, and training on PI;
2. physicians' perceptions and views about the scope of PI at direct care and organizational levels, assessed by asking physicians to rank four given areas of involvement for each level according to their perceived importance, where the area of greatest perceived importance was ranked 1 and the least important area was ranked 4;
3. physicians' experience of their patients' involvement in cancer care in the following categories:
 - patients' level of PI, ranked on a scale from 1 to 10 where 1 = less involved and 10 = more involved. We categorized PI level as low (1-4), moderate (5-7), or high (8-10).
 - physicians' satisfaction with PI, ranked from 1 (less satisfied) to 10 (more satisfied), with ranks categorized as low (1-4), moderate (5-7), or high (8-10).

- phases of patient care, referring specifically to phases of breast cancer care that the physicians' patients had actually experienced: diagnosis, surgery, chemotherapy, hormonal treatment, follow-up, and none (if patient had not experienced any phase).
 - areas of PI, which referred to any of the above phases of care during which patients had had any of the following roles: receiving enough information, sharing in decision-making, and giving feedback.
4. perceived barriers to PI, which physicians ranked from a list as most to least important and which we categorized as patient, physician, or system/organization barriers; and
 5. PI improvement suggestions, which we categorized as related to providers or policymakers and which the physicians ranked from the most to the least important.

The questionnaire was pilot tested, and no modifications were needed. Content validity and face validity of the tool had been secured through review and approval by a panel of experts.

Data management

Data were collected, revised, coded, and fed to statistical software IBM- SPSS, and we considered differences at $p < 0.05$ statistically significant. We used descriptive statistics for data tabulation and presentation, and we present the categorical variables as frequencies and percentage. We used Pearson's correlation coefficients to test correlations between the quantitative variables.

Ethical approval and consent

The study conformed to the international ethics guidelines and that of Helsinki's Declaration. We obtained administrative approvals from the Medical Research Institute Hospital and Ayadi El-Mostakbal Cancer Care Center, and we obtained verbal consent from all participants after we explained the aim of the study. We ensured the confidentiality of all data, and each participant was able to withdraw from the study at any time. The study protocol received ethical approval from the Ethics Committee of the High Institute of Public Health, Alexandria University.

RESULTS

More than half of the physicians (55.3%) were surgeons, and 44.7% were oncologists. Half of the physicians (50.0%) had more than 10 years of experience, and the majority (71%) had received no training on PI.

Physicians' perceptions of PI

Physicians perceived that the most important area of PI in direct care was "getting enough information about their health condition from doctor," followed by "knowing the benefits and risks of different treatments." The doctors ranked "express opinion and observations about the delivered care" as the least important (Figure 1.a).

Figure 1.b shows the physicians' ranks of organizational-

level aspects of PI. “Give her opinion in received service” was ranked the most important area followed by “overall evaluation of service provided by the health institution,”

and the physicians viewed “participation in decisions with the board of directors of the health care institution” as the least important.

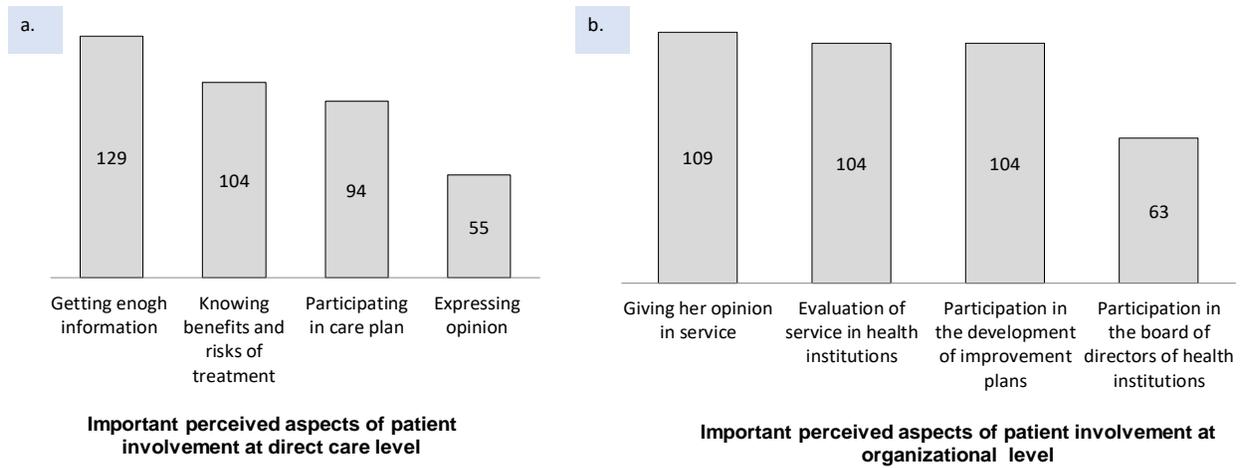


Figure 1: Physicians’ ranks of the importance of patient involvement in breast cancer care at the a. direct care and b. organizational levels

Physicians’ experiences with PI

In terms of actual PI in health care, more than half the physicians (55%) reported moderate patient involvement, and by phase, half the physicians indicated that their patients had been involved in the diagnosis phase. Figure 2 presents the physicians’ rankings of their patients’ involvement in their health-care, and Figure 3 presents the patients’ levels of involvement at each phase of cancer care, as ranked by the study physicians.

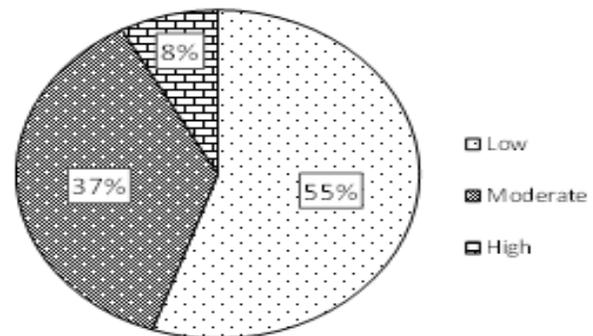


Figure 2: Patients’ involvement in their cancer care as reported by physicians

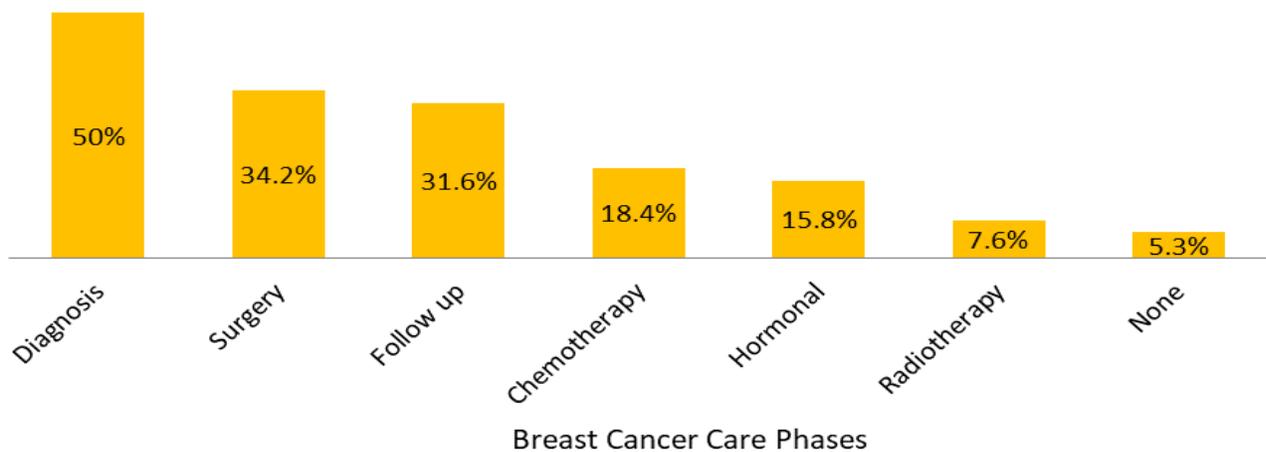


Figure 3: Patients’ actual involvement in cancer care by phase as reported by physicians

Figure 4 presents the different aspects of actual PI that the physicians in this study had observed among their patients. More than half of the physicians, 57.9%, reported that their patients wanted to receive enough

information and to “know the benefits and risks of treatment.” A small percentage of physicians, 13.2%, indicated that their patients had no personal involvement in any areas of their direct care

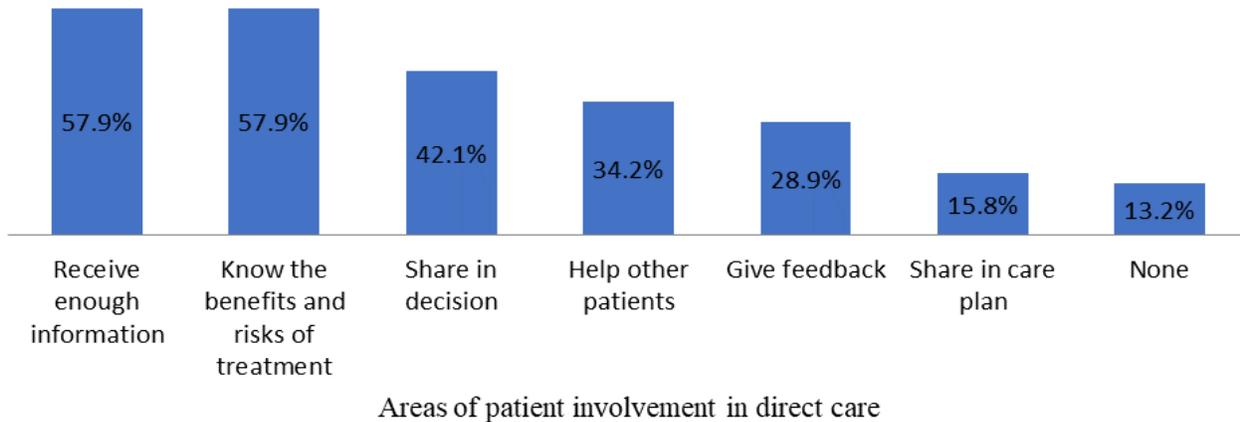


Figure 4: Actual patient involvement in areas of direct breast cancer care as reported by physicians

Physicians in this study were also asked to rate their satisfaction with their patients’ current involvement in their cancer care, and only 8% reported high satisfaction with PI among their patients (Figure 5).

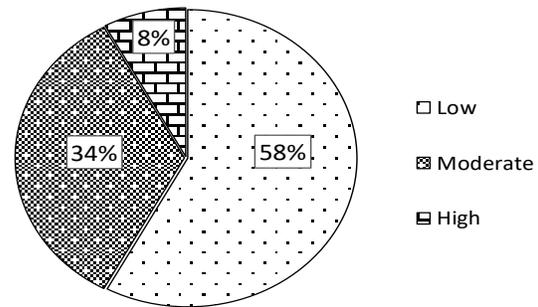


Figure 5. Physicians' satisfaction with the current level of patient involvement in breast cancer care

Figure 6 presents that physicians’ satisfaction with PI correlated strongly and directly with their reported levels of PI ($r = .822, p < 0.05$): The physicians whose patients were more involved in their care were more satisfied with their patients’ levels of involvement.

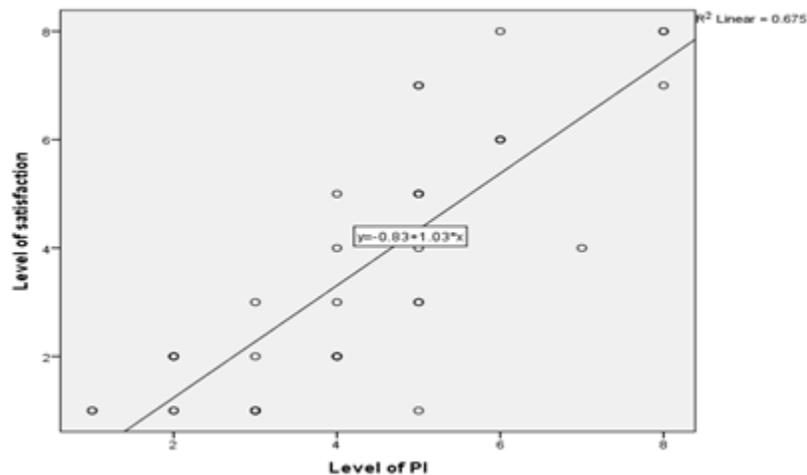


Figure 6: Correlation between patients’ level of involvement (as reported by physicians) and physicians’ satisfaction. r: Pearson’s coefficient, $p = 0.01$

Physicians’ perceived barriers to PI

Figures 7a, b, and c show that physicians ranked “low education and low social level” and “lack of awareness” as the most important patient-related barriers to PI in their cancer care, and among

physician-related barriers, the physicians ranked first “non-consideration of the patient’s opinion.” Among organization-level barriers to PI, the physicians ranked “unavailability of awareness-raising programs” and “complex routine” the highest.

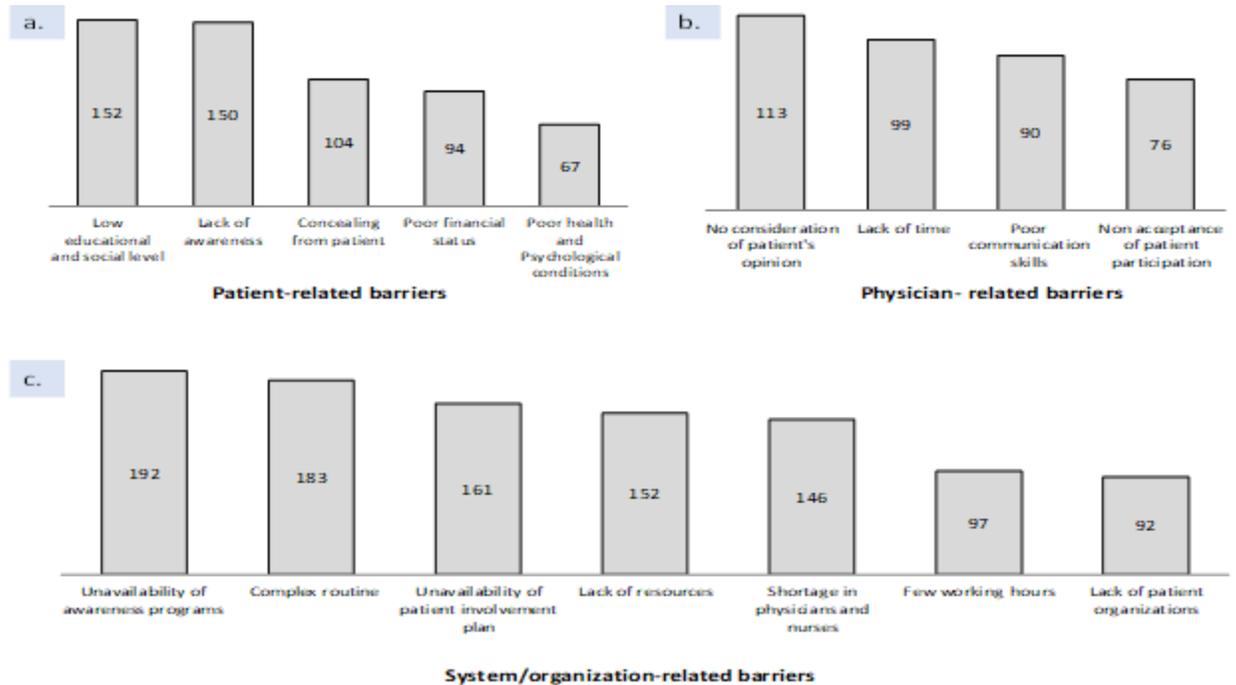


Figure 7: Ranking of barriers to patient involvement in breast cancer care: a. patient-level barriers, b. physician-related barriers, and c. organizational barriers

Physicians’ suggestions to improve PI

Among patient-related suggestions, “give adequate oral and written information” ranked first followed by “encourage patient communication,” while “encourage shared decision-making” ranked last. For policy makers, physicians ranked forming multidisciplinary

teams as the most important suggestion for increasing PI in cancer care followed by designing health education programs and ranked establishing cancer patient organizations as the least important suggestion (Figures 8a and b).

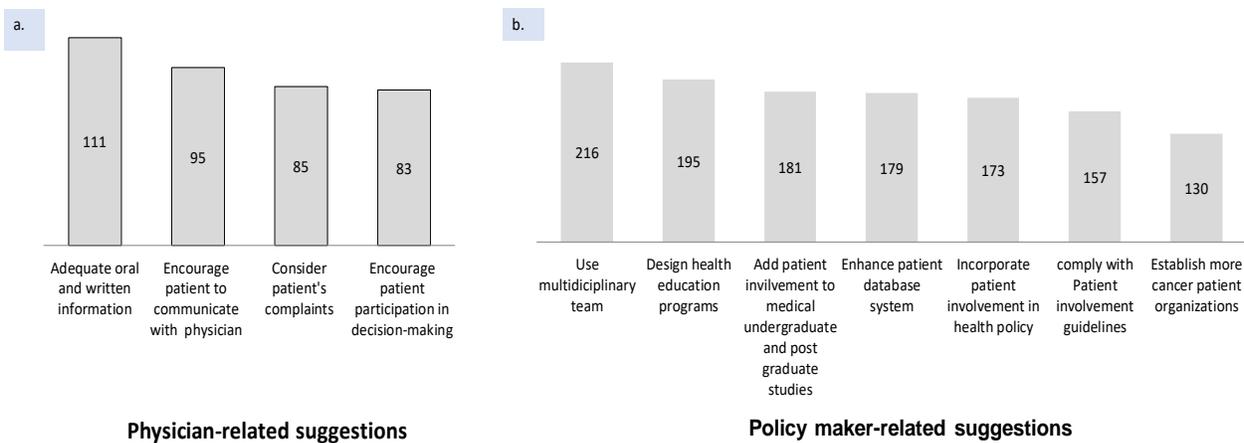


Figure 8: Physicians’ suggestions for improving patient involvement in breast cancer care: a.

b. policymaker-related suggestions.

DISCUSSION

In the current study, only 8% of cancer care physicians reported high levels of involvement among their cancer patients. Physicians who reported active PI mostly described less active forms of involvement such as “getting enough information about their health condition from the physician” and “knowing the benefits and risks of different treatments.” Similarly, in a European Commission study of practitioners, respondents frequently considered the term “PI” to refer to less participative roles such as taking more interest in their health care, asking questions, making themselves better informed, and simply complying with physicians’ prescriptions.⁽¹⁵⁾

Increasing patients’ involvement in their own health care is not a step to be taken overnight; it is a big step that needs to be preceded by changes in physicians’ working conditions but also in their paternalistic attitudes toward their patients. Factors such as these make it unsurprising that the physicians in this study ranked “inserting PI as part of the curriculum for students of the medical college and postgraduates” among the highly rated suggestions for improving patient involvement in care.

A considerable amount of literature supported training health care professionals on shared decision-making and identified lack of training on empathy with patients’ needs as well as a cultural view of the patient as a case rather than a participant as hindrances to PI.⁽¹⁵⁾

Although physicians perceived patient feedback about the quality of health service provided by the health institution to be the most important area of PI at the organizational level, the institutions of the physicians in this study did not appear to have systematic approaches by which patients could communicate their feedback. Indeed, patient feedback closes the gap between macro-level institutional goals and service user expectations and as such could be a significant input in service planning and improvement.⁽¹⁶⁾

Generally, physicians report inadequate patient involvement in decision-making regarding a variety of different cancer treatments, with more involvement in surgery and follow-up decisions and less PI in decisions regarding chemotherapy, hormonal therapy, and radiotherapy. A study in Sweden presented contradictory findings, however: The majority of health care professionals (70%) reported that their workplace had routines for involving patients in discussions and decisions regarding their care and treatment.⁽¹⁷⁾ Wong et al. also showed similar findings.⁽¹⁸⁾

Our findings emphasize the inclination of health care professionals to use the paternalistic approach in dealing with their patients especially when decision-making is required. Physicians in this study revealed that low education, low social level, and lack of awareness were the most important patient-related barriers against PI, and Gravel et al. presented a related finding that patient characteristics were the hindrance to greater PI in shared decision-making.⁽¹⁹⁾ Researchers have reported consistent

results in other studies as well.⁽²⁰⁻²²⁾ However, irrespective of their education levels, all patients have the right to adequate information about their conditions and their treatment plans, including the right to give informed consent to treatment procedures. We and other researchers found that physicians’ lack of time and work overloads were obstacles to more PI in care.^(17, 19, 23, 24)

The health education programs physicians suggested in this study would help give patients sound information from credible sources, which could encourage both patients and physicians regarding PI. Moreover, the physicians in this study suggested that multidisciplinary care teams might help increase their cancer patients’ involvement in their own care. Cancer patients face a particular fight that is much different from that of many other sick patients, and cancer patients need more than medication because they are fighting more than malignant cells. Helping cancer patients in this fight should not fall only on the oncologists or radiologists treating the immediate cancer cells. Additionally, research has begun to focus on environmental and organizational factors that affect PI rather than just individual patient or professional factors,^(17, 25) and in fact, the physicians in this study cited the complex care routine as among the most significant barriers to their patients’ involvement in their cancer care. Researchers such as Gravel et al.⁽¹⁹⁾ have also revealed lack of access to services as an obstacle to PI.

Limitations

This study affords meaningful information supporting future research designed to improve PI in Egypt. However, the present work has some limitations.

- First, the study was conducted in public organizations only, which did not allow for comparison between organizations of different health sectors.
- Second, we used a self-administered questionnaire to assess PI practices that depended on respondents’ perceptions and memories rather than observation.
- Third, we limited our study of PI in the present work to only some of the important areas and did not address other important aspects of PI such as PI utility, risks, and facilitators; self-monitoring and self-care; Internet use; reaching a physician in time of need; and receiving copies of medical records. One of the reasons we limited the PI areas we investigated was to avoid a long questionnaire and thereby increase the response rate.

CONCLUSION AND RECOMMENDATIONS

More than half of the physicians in this study reported low levels of patient involvement in breast cancer care and were not satisfied with these levels, but they lacked supportive systems for promoting PI. The physicians in this study revealed lack of organizational plans related to PI and lack of PI awareness programs and resources (including poor salaries), and they expressed their persistent need for multidisciplinary teams. PI in health care demands great effort at different levels of care. We

suggest using these study findings to generate a framework for integrating PI into Egypt's health care system.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

FUNDING

The current study did not receive any financial support.

REFERENCES

1. James J. Health Policy Brief: Patient Engagement. Health Affairs. 2013 February; 14: DOI: 10.1377/hpb20130214.898775.
2. Arnetz JE, Zhdanova L. Patient involvement climate: views and behaviours among registered nurses in myocardial infarction care. *J Clin Nurs*. 2015 Feb; 24(3-4):475-85.
3. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs*. 2013 Feb; 32(2):207-14.
4. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Sweeney J. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*. 2013; 32(2):223-31.
5. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. *Iran Red Crescent Med J*. 2014 Jan;16(1):e12454.
6. Higgins T, Larson E, Schnall R. Unraveling the meaning of patient engagement: A concept analysis. *Patient Educ Couns*. 2017 Jan;100(1):30-6.
7. Egyptian Ministry of Health and Population (MOHP). Egyptian health care accreditation program standards for hospitals. Egypt: MOHP. 2013.
8. Stub T, Musial F, Quandt SA, Arcury TA, Salamonsen A, Kristoffersen A, et al. Mapping the risk perception and communication gap between different professions of healthcare providers in cancer care: a cross-sectional protocol. *BMJ Open*. 2015 Sep 3;5(9):e008236.
9. Mandelblatt JS, Yabroff KR, Kemer JF. Equitable access to cancer services. *Cancer*. 1999; 86(11):2378-90.
10. Passik SD, Kirsh KL, Rosenfeld B, McDonald MV, Theobald DE. The Changeable Nature of Patients' Fears Regarding Chemotherapy: Implications for Palliative Care. *J Pain Symptom Manage*. 2001; 21(2):113-20.
11. Matthews H, Grunfeld EA, Tumer AJPo. The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer: a systematic review and meta-analysis. *Psycho-oncology*. 2017 May;26(5):593-607.
12. Brebach R, Sharpe L, Costa DS, Rhodes P, Butow P. Psychological intervention targeting distress for cancer patients: a meta-analytic study investigating uptake and adherence. *Psycho-oncology*. 2016 Aug;25(8):882-90.
13. Merckaert I, Libert Y, Messin S, Milani M, Slachmuylder JL, Razavi D. Cancer patients' desire for psychological support: prevalence and implications for screening patients' psychological needs. *Psychooncology*. 2010 Feb;19(2):141-9.
14. Nazione S, Silk KJ. Patient race and perceived illness responsibility: effects on provider helping and bias. *Medical Education*. 2013; 47(8):780-9.
15. European Commission. Eurobarometer Qualitative Study on patient involvement in healthcare. https://ec.europa.eu/eip/ageing/library/eurobarometer-qualitative-study-patient-involvement-healthcare_en. 2012. Accessed 15 Aug 2020. 2012.
16. Wiig S, Storm M, Aase K, Gjestein MT, Solheim M, Harthug S, et al. Investigating the use of patient involvement and patient experience in quality improvement in Norway: rhetoric or reality? *BMC Health Serv Res*. 2013 Jun 6;13:206.
17. Arnetz JE, Winblad U, Arnetz BB, Hoglund AT. Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. *Eur J Cardiovasc Nurs*. 2008 Jun;7(2):113-20.
18. Wong E, Lui S, Cheung A, Yam C, Huang N, Tam W, et al. Views and Experience on Patient Engagement in Healthcare Professionals and Patients—How Are They Different? *Open J Nurs*. 2017 ;7:615-29.
19. Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci*. 2006 Aug 9;1:16.
20. Kimberlin C, Brushwood D, Allen W, Radson E, Wilson D. Cancer patient and caregiver experiences: communication and pain management issues. *J Pain Symptom Manage*. 2004 Dec;28(6):566-78.
21. Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care. *Cancer Nurs*. 2001 Jun;24(3):172-9.
22. Steinhilber KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000 May 16;132(10):825-32.
23. Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clin Proc*. 2010 Jan;85(1):53-62.
24. Mudiyanse RM, Weerasinha GSM, Piyasinha MK. Patient's expectations during doctor patient communication and doctors' perception about patient's expectations in a tertiary care unit in Sri Lanka. *Archives of Medicine*. 2015;7(612):1-5
25. Sahlsten MJM, Larsson IE, Plos KAE, Lindencrona CSC. Hindrance for patient participation in nursing care. *Scand J Caring Sci*. 2005;19(3):223-9.