Patient’s Desire and Preference for Provision of Information Toward Greater Involvement in Shared Care

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ABSTRACT

Objectives: To determine the perceptions of patients on whether they receive sufficient information about their medical problems, their preferences to obtain information, and factors that may influence their preferences.

Design and Settings: Cross-sectional, questionnaire-based study conducted in a primary health-care center affiliated with the National Guard Hospital, Riyadh, Saudi Arabia.

Patients and Methods: Patients attending the center between October and December 2010 were interviewed using a questionnaire developed to meet the objectives of the study.

Results: A total of 245 patients participated in the study. The mean (±standard deviation) age of the participants was 43 (±16) years. Reported cases of dyslipidemia, diabetes mellitus, and hypertension among participants were 42%, 39%, and 31%, respectively. A minority of the participants indicated that they had a sufficient knowledge of their medical problems. The vast majority of the patients (92%) indicated that their preference to be informed about available treatment options and the plan for their future treatment. However, only 38% indicated that they had been told about the available treatment options, and less than half (48%) were informed about their future treatment plan. The proportion of male patients who preferred to know the treatment plan for their medical problems was significantly more than that of females (P < 0.001); nevertheless, female participants perceived that they had been better informed about their treatment plan than the male participants (P = 0.003).

Conclusion: This study demonstrates that patients receive information about their medical problems much less than their expectations. Measures to promote patient education and their involvement in shared care process should be considered and implemented to minimize serious health outcomes.

Key words: Autonomy, health education, patients’ information

ملخص البحث:

هدفت هذه الدراسة تحديد أراء وانطباعات المرضى عن مدى حصولهم على معلومات كافية عن مشاكلهم الصحية، وكذلك العوامل التي قد تؤثر في تلك الانطباعات. وقد شارك في هذه الدراسة المقطوعة 245 مراجعًا إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المراكز الصحية 245 مراجعة إحدى المواقع: www.sjmms.net

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INTRODUCTION

Involvement of patients in the decision-making process is central to the patient-centered approach. This includes the provision of medical information to patients to enable them to make an informed decision regarding their health. Shared decision making between patient and physician is a balanced approach between the two extremes; “paternalism” and “informed consent”. Reports have indicated a higher level of patient satisfaction and greater compliance to treatment when patients have been well-informed of their health status. Also, well-informed patients are likely to be less anxious and have better outcomes.

Patient approval for any medical intervention is mandated both legally and ethically. This process is usually achieved by obtaining “informed consent” from patients, which should explain all the relevant information, including interventions, complications, and the success rate of procedures. Studies have shown that the majority of patients prefer to have adequate information regarding their health. However, this view is remarkably different when it comes to the final decisions about the modality of the interventions.

Information about patients’ preference and involvement in the process of medical decision making in Saudi Arabia is very scarce. This study was carried out in a primary care setting in central Saudi Arabia to determine, whether from a patient’s point of view, adequate information is provided regarding their health, their preferences regarding the level of information that should be provided, and factors that may influence their preferences.

PATIENTS AND METHODS

This is a cross-sectional, questionnaire-based study conducted in a primary health care center in the National Guard Hospital, Riyadh, Saudi Arabia. A total of 245 patients (59% males, 41% females) participated in the study, with a mean (±standard deviation) age of 43 (±16) years. The study was conducted during the period from October to December 2010 and was approved by the Ethics Committee of the King Abdullah International Medical Research Center.
as reported by participants, were highly prevalent, primarily dyslipidemia (42%), diabetes mellitus (39%), and hypertension (31%), with 73% of the participants reporting that they were receiving pharmacological agents for their disease.

Patients with diabetes mellitus or bronchial asthma represented 25% and 27% respectively, of the total study group, with only a quarter of these patients indicating that they had enough general information about their disease. This was considerably less than those suffering from dyslipidemia (10%) and hypertension (12%). The patients’ perception about whether they thought they had received adequate information related to complications of these chronic diseases showed that 37% of diabetic patients and more than half of patients with dyslipidemia, hypertension, and bronchial asthma thought that insufficient information had been given.

Table 2 shows the views of patients on the appropriateness of the treatment received; the majority of patients thought that they had received the most appropriate treatment. The vast majority of the patients (92%) indicated that they preferred to be informed of the available treatment options and the plan for their future treatment. However, only 38% of the participants indicated that they had been informed about the available treatment options, and less than half (48%) had been informed about the future treatment plan.

Further analysis of the data and the effects of personal and demographic characteristics showed that the gender of the participants played a significant role in the preference and perception of the treatment plan and options. The data in Table 3 show that female participants perceived that they had been better informed than the male participants about the available treatment options for their medical problems ($P < 0.001$). Interestingly, the proportion of male patients who preferred to know the treatment plan for their own diseases (138 (95%)) was significantly greater than that of females (87 (88%)) ($P < 0.001$). Nevertheless, female participants perceived that they had been better informed about their treatment plan than male participants ($P = 0.003$).

### Table 1: Sociodemographic characteristics of patients ($n = 245$)

| Characteristic | $n$ (%) |
|---------------|--------|
| **Sex**       |        |
| Male          | 145 (59.2) |
| Female        | 99 (41.4)  |
| Missing       | 1 (0.4)    |
| **Marital status** |    |        |
| Married       | 28 (11.4)  |
| Single        | 196 (80)   |
| Divorced      | 7 (3)      |
| Widowed       | 13 (5.3)   |
| Missing*      | 1 (0.4)    |
| **Educational level** |     |        |
| Illiterate    | 42 (17)    |
| Read and write| 22 (9)     |
| Elementary/Intermediate | 88 (36) |
| Secondary     | 60 (24)    |
| Higher than secondary | 29 (12) |
| Missing*      | 4 (2)      |

*Data not given by participants or not available.

### Table 2: Perception of patients regarding receiving information about their chronic diseases

| Received information | DM $n$ (%) | Hypertension $n$ (%) | Dyslipidemia $n$ (%) | Bronchial asthma $n$ (%) |
|----------------------|------------|----------------------|----------------------|--------------------------|
| **Information about disease** |          |                      |                      |                          |
| Yes                  | 24 (25)    | 9 (12)               | 10 (10)              | 12 (27)                  |
| To some extent       | 41 (43)    | 36 (47)              | 49 (48)              | 15 (34)                  |
| Do not know          | 30 (32)    | 32 (41)              | 43 (42)              | 16 (36)                  |
| **Future complication** |          |                      |                      |                          |
| Yes                  | 21 (22)    | 10 (13)              | 8 (8)                | 10 (23)                  |
| To some extent       | 38 (40)    | 27 (35)              | 41 (40)              | 7 (16)                   |
| Do not know          | 35 (37)    | 40 (52)              | 53 (52)              | 25 (57)                  |
| **Appropriate treatment** |          |                      |                      |                          |
| Yes                  | 63 (66)    | 51 (66)              | 70 (69)              | 30 (68)                  |
| To some extent       | 14 (15)    | 11 (14)              | 20 (20)              | 4 (9)                    |
| Do not know          | 10 (11)    | 9 (12)               | 5 (5)                | 4 (9)                    |
| **Total number of respondents** | 95 (100)   | 77 (100)             | 102 (100)            | 44 (100)                 |

DM – Diabetes mellitus
DISCUSSION

The reported cases of chronic diseases in the study sample were high compared to locally available data.\(^\text{[8,9]}\) However, these study findings need to be verified by confirmatory laboratory tests and further community-based studies. The findings of this study as well as the available published data pertaining to the prevalence of chronic diseases among Saudi patients necessitate urgent consideration of implementing more effective measures in the management of chronic diseases, such as efficient programs for patient education and more patient involvement in managing their own medical problems. Effective involvement of patients in the management of their chronic diseases requires providing them with adequate information about the nature of their illness, future complications, and available treatment options. The provision of this information could enhance the shared decision-making process, promote better patient care, and minimize future risks of these chronic medical conditions.\(^\text{[6]}\) Exploring patients’ knowledge regarding their medical problems and their preference for more involvement in the management of their medical problems is probably the most essential step in planning and implementing efficient shared-care programs.

This study showed that only a small percentage (18%) of patients perceived that they had received adequate information about their medical problems and complications of their illness. However, more than 60% of the patients included in the study thought that they received the appropriate treatment. Patients’ understanding and preparedness in involvement in the management of their medical problems are certainly the first and most important steps in the process of achieving better care and better outcomes. This study also showed that patients are prepared and actually want to have more information about their medical problems and treatment options and plans, which is in line with a previous study which found that patients are dissatisfied with the amount of information and disclosure in clinical informed consent before procedures are carried out in a Saudi tertiary care center.\(^\text{[10]}\)

Studies that reported the patients’ desire for information in Western and Eastern cultures have shown similar findings, with the majority of patients indicating that the amount of information given by their physicians was below their expectations.\(^\text{[11,12]}\) Information disclosure and involvement in clinical decision-making are significantly influenced by culture, particularly if they are related to terminal diseases and cancer.\(^\text{[11]}\) Most patients prefer the involvement of family members in information disclosure of incurable illnesses. This family-centered model of care is somewhere midway between the patient-centered models favored by patients in Western countries and the preference of Japanese patients.\(^\text{[10,13]}\) However, the views of patients and physicians regarding the level of disclosure are not always aligned. This necessitates the need for recognition and acknowledgment of patients’ autonomy.\(^\text{[14]}\)

| Characteristics of patients | Do you prefer to know the treatment options? | Have you been told the treatment options? | Do you prefer to know the treatment plan? | Have you been told about the treatment plan? |
|-----------------------------|---------------------------------------------|-------------------------------------------|-------------------------------------------|---------------------------------------------|
|                             | Yes | No | Yes | No | Yes | No | Yes | No |
| Sex                         |     |    |     |    |     |    |     |    |
| Male                        | 138 | 6  | 45  | 99 | 142 | 1  | 63  | 80 |
| Female                      | 87  | 5  | 49  | 41*| 82  | 7i| 50  | 38*|
| Marital status              |     |    |     |    |     |    |     |    |
| Single                      | 27  | 1  | 5   | 23 | 28  | 0  | 13  | 15 |
| Married                     | 180 | 8  | 74  | 112| 179 | 5  | 85  | 98 |
| Divorced                    | 7   | 0  | 5   | 2  | 6   | 1  | 5   | 2  |
| Widow                       | 11  | 2  | 10  | 3i | 11  | 2  | 10  | 3  |
| Level of education          |     |    |     |    |     |    |     |    |
| Illiterate                  | 41  | 1  | 25  | 17 | 42  | 1  | 22  | 19 |
| Read and write              | 18  | 3  | 8   | 15 | 17  | 3  | 10  | 14 |
| Elementary and intermediate | 82  | 5  | 35  | 52 | 83  | 3  | 44  | 41 |
| Secondary                   | 57  | 1  | 20  | 38 | 57  | 1  | 28  | 30 |
| Higher than secondary       | 24  | 1  | 6   | 18 | 25  | 0  | 9   | 14 |
| Total number of respondents | 225 | 11 | 94  | 140| 224 | 8  | 113 | 118 |

\(^*P < 0.001; ^\text{\textbar}P < 0.001; ^\text{\textbar}P = 0.003; ^{\text{i}}P = 0.001; \text{Chi-square-test}\)
The observed difference that females perceived that they were better informed than males about treatment options and treatment plan is probably related to issues such as inherently different communication skills of patients and physicians.\textsuperscript{[15]} It has been found that adult patients usually have high information-seeking preference. This preference, however, is influenced by factors such as gender and age of both physicians and patients and the nature of patients’ illnesses.\textsuperscript{[16-18]} Interestingly, the preference to have more information does not always indicate the preference of a patient to be involved in the decision-making process; studies have shown that the majority of patients preferred to leave the decision about their medical problems to their physicians.\textsuperscript{[19,20]}

Published data from different settings showed that the desire for more information was found to be higher among more educated patients. In this study, however, this association did not reach statistical significance. This may be better demonstrated in a large sample size from multicenter future studies.\textsuperscript{[21,22]}

Provision of appropriate information to patients that respond to his/her needs and concerns is essential for appropriate reassurance and further compliance to the selected treatment and treatment plan. A key to effective reassurance is based on the physicians’ ability to respond and acknowledge patients’ understanding and need for information.\textsuperscript{[23,24]}

This study demonstrates that the level of information that patients receive about their medical problems is much lower than their expectations. A variety of strategies that promote health education were widely implemented. These vary from simple health education activities to sophisticated and costly techniques that utilize high technology. These strategies aim to reinforce or modify patients’ behavior, improve compliance, as well as to improve patients’ ability for acquisition of problem solving skills in their medical chronic conditions. These interventions could be offered for individual patients face to face or to a group of patients, led by a trained member of the treating staff, or use a technology, such as simple or sophisticated computer-based programs. However, the effectiveness of educational activities that aim to promote patients’ knowledge about their medical problems varies remarkably.\textsuperscript{[25-27]}

We acknowledge the limitations of this study. This study was conducted in a single family practice center in the Riyadh area. However, multicenter studies are needed to confirm the findings of this study and to evaluate other contributing factors related to patients’ desire for information and more active involvement in the process of shared clinical decision-making. Socioeconomic status factors that could influence the preference of patients, such as “occupation”, were not measured in this study. This particular point should be explored in future studies.

**CONCLUSIONS AND RECOMMENDATIONS**

Patients’ involvement in clinical decision making is essential for better compliance and outcomes. This is only achievable by the provision of adequate and accurate information to patients. This study demonstrated that patients have a positive attitude toward receiving information about their medical status and available treatment options. Certain demographic characteristics were found to influence patients’ preference; however, future multicenter studies are needed to confirm the results of this study and any other influencing factors.

Future studies are recommended, especially in areas related to exploring patients’ awareness about their rights in the decision-making as well as physicians’ awareness of the patient-centered approach. Measures and strategies that promote patient education and self-care should be implemented. However, it is important to consider effectiveness, acceptability, applicability and continuity, and the cost of these strategies in order to have a significant impact on improving the quality of life and health outcomes of patients.

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**Conflicts of interest**

There are no conflicts of interest.

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