

Patient Engagement in Decision Making and Associated Factors among Outpatients with Selected Non-Communicable Chronic Diseases in Public Hospitals of West Shoa, Ethiopia,2020

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Research Article

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Abstract

Background: Despite the importance of patient engagement in health care decision-making in the care of patients with chronic diseases, there is limited information about it and the factors affecting it in Ethiopia in general and in the Public Hospitals of West Shoa in particular. Thus this study is designed to assess the engagement of patients with selected chronic non-communicable diseases in health care decision making and associated factors in public hospitals of West Shoa Zone, Oromia, Ethiopia.

Methods: Facility-based cross-sectional study design was used. Systematic sampling was used for the selection of study participants from June 7 – July 26, 2020. Standardized, pretested, and structured Patient Activation Measure was used to measure patient engagement in healthcare decision-making. Descriptive analysis was done to determine the magnitude of patient engagement in health care decision-making. Multivariate logistic regression analysis was used to determine factors associated with patients' engagement in the health care decision-making process. Adjusted odds ratio with a 95% confidence interval was calculated to measure the strength of association. Statistical significance was declared at $p < 0.05$. The results were presented by tables and graphs.

Results: A total of 406 patients with chronic diseases participated in the study yielding a response rate of 96.2%. Less than a fifth [19.5% (95% CI: 15.5, 23.6)] of participants in the study area had a high engagement in their health care decision-making. Educational level (college or above) [AOR=5.2, 95% CI (1.76-15.46)], duration of diagnosis >5 years [AOR= 1.8, 95% CI (1.03-3.2)], health literacy [AOR=1.15, 95% CI (1.06-1.24)], autonomy preference in decision making [AOR=1.35, 95% CI (1.03-1.96)] were factors significantly associated with participants' engagement in health care decision making among patients with chronic diseases.

Conclusion- Low number of respondents had a high engagement in their health care decision-making. Preference for autonomy in decision making, educational level, health literacy, duration of diagnosis with the disease were factors associated with patient engagement in health care decision making among patients with chronic diseases in the study area. Thus individualized patient-centered care and patient empowerment is essential among patients with chronic non-communicable diseases.

Introduction

Patient Health Engagement Model (PHE) defined patient engagement as, a multidimensional, psychosocial process that results from cognitive, emotional, and behavioral enacting of patients towards their disease and its management(1). Further, it is defined as the degree of active involvement people have in taking care of their health and in determining their care(2). Patient engagement is a dynamic and evolutionary process in which the patient proceeds through the four phases; blackout, arousal, adhesion, and eudemonic project, to achieve full engagement (1). Across the phases, patients acquire knowledge and become more confident and differently engaged in decision making based on their emotional, cognitive and behavioral mindset(1,3).

Chronic non-communicable diseases are the causes for two-thirds of deaths each year causing 42% of premature deaths,80% of which occurs in developing countries (4). A recent study in Ethiopia showed that more than 75% of follow-up for chronic non-communicable disease is due to the three chronic diseases (heart diseases, hypertension, and diabetes mellitus)(5).

Non-communicable chronic diseases need lifelong care and need not only care providers; but also a paradigm shift to team-based care in which patient and care providers work together for control and prevention of disease-related complications(6). This necessitates the involvement of patients in all aspects of the care, including decision-making around medical management(7,8). When patients engage in their healthcare decision-making, they are better able to make informed decisions about their care options, guarantee better use of resources, feel confident to put their viewpoints and promote mutual understanding and accountability with their health care providers. Moreover, it enhances patient and provider satisfaction (9), makes patients familiar with their medication or treatment plans, and finally increases adherence to their overall treatment (2,10).

Chronic patients who have less active engagement levels are more likely to be hospitalized and re-admitted leading to higher health care costs (11). Patients with lower engagement had health care expenses than those with higher engagement levels (12) and attend the emergency department frequently (13). Low engagement in health care is also supposed to decrease implementation of chronic care thus increasing the burden of chronic diseases(14). Less actively engaged individuals are more likely to have unmet medical needs and delay their medical care (2). Further low engagement level is a risk for poor self-care behavior(15). However, in our country, there is limited evidence on the status of patients' engagement in decision-making in their health care and the factors affecting it.

Methods And Materials

Study area and period

The study was conducted in randomly selected public hospitals of west Shoa zone from June 7 – July 26, 2020. West Shoa is one of the zones of Oromia Regional State. It has 8 public hospitals. The hospitals have separate outpatient department for treatment of chronic diseases like cardiovascular diseases, diabetic mellitus, and other chronic diseases.

Study design

Facility based cross sectional quantitative study design was used.

Source population

All patients with non-communicable chronic diseases who were 18 years old and above and who were on follow up at outpatient department in public Hospitals of West Shoa.

Study population

All patients with non-communicable chronic diseases who were ≥ 18 years old and above who were on follow up at the randomly selected public hospitals of West Shoa Zone during study period

Eligibility criteria

Inclusion criteria

Patients with non-communicable chronic diseases who were ≥ 18 years old and on follow up at the time of data collection and those who were able to give response.

Exclusion criteria

Outpatients with selected chronic non-communicable diseases who were not able to respond to the interview

Sample size Determination and sampling technique

The sample size for this study was calculated using single population proportion formula. It was calculated considering proportion (P) of patients' engagement in health care decision making as 50%, margin of error (d) =5% and confidence interval of 95%. Then final sample size was obtained by adding 10% non-response rate and it became 422.

Sampling technique

From eight hospitals in west Shoa, four Hospitals were randomly selected using simple random sampling. From the previous month's patient flow, total of 936 chronic patients (597 patients with cardio vascular diseases and 339 patients with DM) were taken as base line for sampling. Then patients were proportionally allocated to each selected hospitals.

Variables

Dependent variable –Patient engagement in health care decision making

Independent variables –Socio-demographic characteristics of patients (Age, Sex, monthly income, place of residence, educational status), patients' clinical characteristics (Duration of diagnosis with the disease), patients' health related behaviors (Health literacy, Participants' autonomy in decision making) were included.

Operational definitions

High engagement in health care decision making process –Participants were said to have high engagement in health care decision making if scored equal and above 55.1% on patient activation measure

Low engagement in health care decision making process –Participants were said have low engagement in health care decision making if scored below 55.1% on patient activation measure

Patients with chronic non-communicable diseases – according to this study, Patients with chronic non communicable diseases are patients with cardiovascular diseases and Diabetes Mellitus who have attended their appointment at least for 6 months.

Data collection tools and technique

The standardized Patient Activation Measure(PAM-13) questionnaire was used to measure patient engagement in health care decision making process(16). Autonomy Preference Index (API) was used to measure patients' preference for autonomy in health care decision making (17). Health Literacy Questionnaire(18) was used to measure participants health literacy.

Data quality control and management

Prior to data collection, reliability of tools was checked on pretest. English language prepared questionnaires were translated to local language (Afaan Oromoo) and then back to English by different translators to check consistency of the translation. Further data quality was maintained through orientation of data collectors and supervisors on data collection tools.

Data processing and analysis

Completed questionnaires were coded, entered and cleaned using EPIDATA version 3.1 computer program and then exported to SPSS version 23.0 for analysis. Descriptive statistics were used to calculate the frequency distribution, proportions (for categorical variables) and mean, standard deviation, range were used for continuous variables. The outcome variable was analyzed from the data collected using a PAM questionnaire by summing up the total engagement level from 13 items of the patient activation measure with 4 points Likert scale (1=strongly disagree, 2=disagree, 3=Agree, 4= strongly agree). It was treated as binary variable. Accordingly participants with score 55.1% or more were coded 1=high engagement in decision making; and those with lower than 55.1% were coded 0=low engagement in decision making. A Bi-variable logistic regression analysis was done to see the association between each independent variable and the outcome variables. Variables with p-value <0.25 in the bi-variable logistic regression analysis were a candidate for multivariable logistic regression analysis. The logistic regression model fitness was checked using Hosmer-Lemeshow. Multicollinearity was checked using VIF. Both crude and adjusted odds ratio along with 95% CI were estimated to measure the strength of association. The level of statistical significance was declared at a p-value of less than 0.05. Tables and figures were used to display the results.

Ethical and legal consideration

An ethical clearance was obtained from Institutional Health Research Ethics Review Committee (IHRERC) of Ambo University College of Medicine and Health Science. Oral consent was taken from the participants before the interview. In addition, no personal identifiers were used on data collection questionnaire and the data obtained from the study participants were not accessed by anybody except the investigator and were kept confidentially. Further preventive measures against COVID-19 was taken throughout data collection. The participants were assured that they have the right to refuse or withdraw if they were not comfortable at any time.

Results

Socio-demographic characteristics of participants

A total of 406 patients with chronic diseases were involved in the study making an overall response rate of 96.2%. Two hundred nineteen (51.5%) of the participants were males and majority (337(83.2%)) of the participants were above the age of 30 years (Table 1).

Participants' clinical characteristics

Of the 406 patients with chronic diseases, 167(41.1%)) were hypertensive patients and 282 (69.5%) of the participants were less than 5 years since they started their follow up. Nearly a fifth of the participants (18.7%) had

family history of the same chronic diseases and large proportions (70.9%) of the participants do not have history of previous hospitalization with their current disease (Table 2).

Participants' preference for autonomy in decision making

The mean score and standard deviation of autonomy preference in decision making was 75.92 (SD \pm 11.6) with range 35 to 95. (Table 3)

Participants' Health literacy

The mean and standard deviation of health literacy score of participants was 10.48 (SD \pm 3.6). (See Table 4)

Patient engagement in healthcare decision making

The mean score of participants' engagement in health care decision making was 51.07 [(95% CI: 50.4, 51.7)] with standard deviation of (\pm 6.6) [(95% CI (5.9, 7.2)]. By dichotomizing the score, significantly lesser proportion; 19.5% [95% CI: 15.5, 23.6]] of the participants in the study had high engagement in their health care decision making process. (Figure 1)

Factors associated with patient engagement in health care decision making

In multivariable logistic regression analysis, participants with higher educational level (college or above) were about 5 times [AOR=5.2, 95% CI (1.76-15.46)] more likely to be engaged in their health care decision making than those with no formal education. Participants with five year and above duration of diagnosis were about two times [AOR= 1.8, 95% CI (1.03-3.2)] more likely to be engaged in their health care decision making when compared with those who had duration of diagnosis less than five year.

The study also indicated, For every one point increase in participant's health literacy score, the log odds that the participants will have high engagement in their health care decision making increases by 0.14 [B=0.14,AOR=1.15,95% CI(1.06-1.24)] on average. On the other hand the log odds that participants will have high engagement in their health care decision making increases by 0.3[B=0.3, AOR=1.35, 95% CI (1.03-1.96)] on average for one point increase in participant's preference for autonomy in decision making score at p-value less than 0.05(Table 5).

Discussion

This study was conducted to assess patient engagement in health care decision making and associated factors among patients with chronic diseases in public Hospitals of West Shoa Zone. It showed 19.5% of the participants had high engagement in their health care decision making and health literacy, preference for autonomy, educational level, duration of diagnosis were variables associated with patient engagement in health care decision making.

The finding of this study is lower than the finding of the study in Malaysia, Australia in which 61.8% and 68% of the participants respectively had high engagement (19) (20) . The reason for these disparities might be the difference in policy and health care system between the countries; like implementation of Teleprimary Care and

Patient Centered Medical Home which is not in effect in our country. On the other hand the result is higher than the study finding in Nepal(21); in which 6.6% of the of participants had high engagement. This difference might occur due to difference in the study population.

Participants with educational level at college or above were about five times (AOR=5.2) more likely to engage in health care decision making compared with those who have no formal education. The reason might be more educated individuals are more involved in therapeutic communication than uneducated individuals and more committed to incorporate medical advice(22). This result is supported by Study in Nepal (21), Turkey (23), and Australia(24).

Duration of diagnosis is significantly associated with patients' engagement in health care decision making. Patients with duration of diagnosis greater than five years were about two times (AOR=1.8) more likely to engage in their health care decision making when compared with their counter parts. This might be attributed to patient's behavioral change overtime and experiential knowledge patients gained about their illness over a period of time (25). The finding is in line with the study in Australia (24) and China (26). But study in Ethiopia showed no significant association between duration of diagnosis and engagement in health care decision making(27).

The likelihood of engagement in decision making increase [$\beta = 0.14$, AOR=1.15] as health literacy score increases. This might be due to individual's initiation to ask questions and decide on sound treatment options as they build up knowledge about their medical conditions(28). It is supported by Health Information Seeking Behavior Model and also in line with the findings of the study in Malaysia(19), Singapore (29),Denmark (30) ,Nepal (21) and England(31). Contrary to this, study conducted in Canada revealed no association between patient engagement in healthcare decision making and health literacy (32). The possible reason for this difference might goes to socio demography of the population and small sample size of the study.

Patients' preference for autonomy was significantly associated ($\beta = 0.3$, AOR=1.35) with their engagement in health care decision making. The reason behind this might be due to the self-determination to perform a specific action as autonomy increases and intrinsic motivation of individuals to make decision which is justified by Middle Range Theory of nursing and self-determination theory (33,34). Study finding from New Jersey (35) and Italy also support the present finding (36).

Conclusion And Recommendation

In conclusion, the result of this study showed that, participants' engagement in their healthcare decision making is low and Health literacy, duration of diagnosis with the disease, educational level and patients' preference for autonomy in decision making were variables significantly associated with patients' engagement in health care decision making among patients with chronic diseases. Thus patient centered care and shared clinical decision making should be encouraged in the study area. In addition patient activation level needs to be measured at each follow up visit so as to check the improvement in patients' engagement level.

Declarations

Ethical Approval and consent to participate

An ethical clearance was obtained from Institutional Health Research Ethics Review Committee (IHRERC) of Ambo University College of Medicine and Health Science. Oral consent was taken from the participants before the interview. In addition, no personal identifiers were used on data collection questionnaire and the data obtained from the study participants were not accessed by anybody except the investigator and were kept confidential. Further preventive measures against COVID-19 was taken throughout data collection. The participants were assured that they have the right to refuse or withdraw if they were not comfortable at any time.

Consent for publication

Not applicable to this manuscript

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

All concerned body involved in this manuscript either financially and technically were appraised. So We declare that we are accountable to any conflict of interests if any.

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Authors contribution

All authors were involved in designing the study, analyzing the data and manuscript development. Accordingly

Desalegn Emana Jabana: Manuscript preparation

Mulu Kitaba Negewo : Reviewed and edited the write up of the manuscript

Teka Girma: Reviewed and edited the write up of the manuscript

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Table

Table 1: Socio-demographic characteristics of patients with chronic diseases in public hospitals of West Shoa, Ethiopia (n=406), 2020.

| Variable | Categories | Frequency | Percentage |
|---------------------------------|------------------------|------------------|-------------------|
| Sex of participant | Male | 209 | 51.5 |
| | Female | 197 | 48.5 |
| Age of participant | ≤29 | 68 | 16.7 |
| | 30-44 | 118 | 29.1 |
| | 45-59 | 123 | 30.3 |
| | ≥60 | 97 | 23.9 |
| Religion | Orthodox | 151 | 37.2 |
| | Protestant | 185 | 45.6 |
| | Muslim | 33 | 8.1 |
| | Wakefata | 31 | 7.6 |
| | Others* | 6 | 1.5 |
| Residence place | Urban | 184 | 45.3 |
| | Rural | 222 | 54.7 |
| Ethnicity | Oromo | 368 | 90.64 |
| | Amhara | 31 | 7.64 |
| | Gurage | 7 | 1.72 |
| Marital status | Single | 74 | 18.2 |
| | Married | 284 | 70.0 |
| | Widowed | 35 | 8.6 |
| | Divorced | 13 | 3.2 |
| Educational status | No formal education | 90 | 22.2 |
| | Elementary(grade 5-8) | 169 | 41.6 |
| | Secondary school(9-12) | 85 | 20.9 |
| | College/university | 62 | 15.3 |
| Participant's occupation | Farmer | 116 | 28.6 |
| | Government employee | 32 | 7.9 |
| | Self-employee | 144 | 35.4 |
| | Retired | 29 | 7.1 |
| | Student | 33 | 8.2 |
| | House wife | 52 | 12.8 |

| | | | |
|---|--------------------|-----|------|
| Participant's average monthly income | <1000ETB | 316 | 77.8 |
| | ≥1000ETB | 90 | 22.2 |
| Participants source of health information about their illness | Reading book | 30 | 7.4 |
| | News paper | 7 | 1.7 |
| | Health care worker | 406 | 100 |
| | Television | 97 | 23.6 |
| | Radio | 98 | 24.1 |
| | Others** | 8 | 2.0 |

*=Catholic, 'Waaqa' ('Qaallicha') ETB=Ethiopian birr

**= internet, friends, family members

Table 2: clinical characteristics of patients with chronic diseases in public hospitals of west Shoa, Central Ethiopia (n=406), July, 2020.

| Variables | Categories | Number | Percentage |
|---|-------------------|--------|------------|
| Type of disease for which they are on follow up | Hypertension | 167 | 41.1 |
| | Diabetes mellitus | 144 | 35.5 |
| | Heart disease | 95 | 23.4 |
| Family history of the same chronic disease | Yes | 76 | 18.7 |
| | No | 330 | 81.3 |
| Duration since diagnosed with disease | <5yrs. | 282 | 69.5 |
| | ≥5 yrs. | 124 | 30.5 |
| Previous history of hospitalization with the disease | Yes | 118 | 29.1 |
| | No | 288 | 70.9 |
| Patients' awareness of their right to make treatment decision | Yes | 287 | 70.7 |
| | No | 119 | 29.3 |
| Do you search for information intentionally in advance to your health care provider's advice? | Yes | 190 | 46.8 |
| | No | 216 | 53.2 |

Table 3: Preference for autonomy in decision making among patients with chronic diseases in Public Hospitals of West Shoa Zone, Central Ethiopia 2020 (n=406).

| Variables (items of preference for autonomy) | Disagree | | Agree | |
|--|----------|------|-------|------|
| | F | % | F | % |
| 1 The important medical decisions should be made by your care provider, not by you | 69 | 16.9 | 337 | 83.1 |
| 2 You go along with your care provider's advice even if you disagree with it. | 52 | 12.8 | 354 | 87.2 |
| 3 You should not be making decisions about your own care | 94 | 23.1 | 312 | 76.9 |
| 4 As your illness became worse you would want your doctor to take greater control | 124 | 30.5 | 282 | 69.5 |

Table 4: Participants' health literacy in Public Hospitals of West Shoa Zone, Central Ethiopia 2020 (n=406).

| Variables | Difficult | | Easy | |
|--|-----------|------------|-----------|------------|
| | Frequency | percentage | Frequency | Percentage |
| Find information about your health problem | 334 | 82.26 | 72 | 17.74 |
| Find health information from different places | 326 | 80.3 | 80 | 19.7 |
| Get information about your health so you are up to date about your illness | 270 | 66.5 | 136 | 33.5 |
| Get health information in words you understand | 279 | 68.7 | 127 | 31.3 |

Table:5 Factors associated with patient engagement in health care decision making(n=406) in public hospital of West Shoa Zone, Central Ethiopia, 2020

| variable | Categories | Patient engagement in health care decision making | | Odds Ratio with 95% CI | |
|-----------------------------------|---------------------|---|-------------|------------------------|------------------------------|
| | | High | Low | Crude OR | Adjusted OR |
| Sex | Male | 37(9.1%) | 172(42.4%) | 1 | 1 |
| | Female | 42(10.3%) | 155(38.2%) | 1.26(0.77,2.06) | 1.7(0.97,3.07) |
| Age | age ≤29 | 18(4.4%) | 50(12.3%) | 2.3(1.03,5.1)* | 1.2(0.46,3.13) |
| | age 30-44 | 29(7.1%) | 88(21.7%) | 2.1(1.02,4.32)* | 1.18(0.5,2.8) |
| | age 45-59 | 19(4.7%) | 106(26.1%) | 1.14(0.53,2.4) | 0.8(0.35,2.01) |
| | age ≥60 | 13(3.2%) | 83(20.4%) | 1 | 1 |
| Educational status | No formal education | 7(1.7%) | 83(20.4%) | 1 | 1 |
| | Elementary grade | 22(5.4%) | 147(36.2%) | 1.7(0.72,4.3) | 2.1(0.82,5.42) |
| | Secondary school | 20(4.9%) | 65(16.0%) | 3.6(1.45,9.15)* | 3.4(1.26,9.6)** |
| | College/university | 30(7.4%) | 32(7.9%) | 11.1(4.4,27.84)* | 5.2(3.24,16.33)** |
| Residence place | Urban | 44(10.8%) | 140(34.5%) | 1.67(1.02,2.75)* | 1.1(0.62,1.95) |
| | Rural | 35(8.6%) | 187(46.1%) | 1 | 1 |
| Monthly income | <1000 ETB | 50(12.3%) | 266 (65.5%) | 1 | 1 |
| | ≥1000 ETB | 29(7.1%) | 61(15.0%) | 2.5(1.48,4.32)* | 1.3(0.66,2.57) |
| Duration of diagnosis | ≥5 years | 36(8.9%) | 88(21.7%) | 2.27(1.37,3.77)* | 1.8(1.03,3.2)** |
| | <5years | 43(10.6%) | 239 (58.9%) | 1 | 1 |
| Preference for autonomy in | | | | 1.54 (1,1.059)* | 1.35(1.03,1.96)** β=0.3 |
| Health literacy | | | | 1.2(1.1,1.27)* | 1.15(1.06,1.24)** β =0.14 |

** Significant at p-value<0.05

Figures

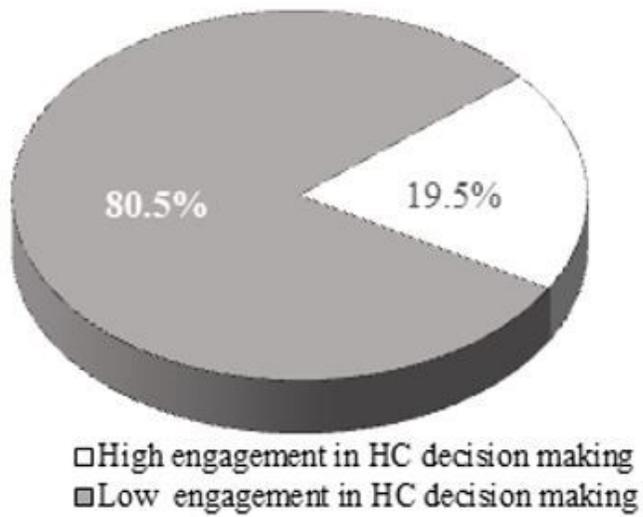


Figure 1

Patients' Engagement in health care decision making. Patients' engagement in health care decision making among patients with chronic diseases in public hospitals of West Shoa Zone, July 2020

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Tables.docx](#)