

A CROSS-SECTIONAL ASSESSMENT OF SHARED-DECISION MAKING AMONG PATIENTS VISITING PUBLIC HEALTHCARE INSTITUTE OF QUETTA CITY, PAKISTAN

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Published online: 31 May 2020

To cite this article: HIRA WAHEED, SAJJAD HAIDER, QAISER IQBAL, ADNAN KHALID, MOHAMED AZMI HASSALI, MOHAMMAD BASHAAR & FAHAD SALEEM (2020) A cross-sectional assessment of shared-decision making among patients visiting public healthcare institute of Quetta City, Pakistan, *Malaysian Journal of Pharmaceutical Sciences*, 18(1): 15–29, https://doi.org/10.21315/mjps2020.18.1.2.

To link to this article: https://doi.org/10.21315/mjps2020.18.1.2

Shared-decision making (SDM), occasionally called "participatory governance" is the approach in healthcare to ensure that patients have the right to participate effectively in the decision-making (DM) process. The aim of this research was to discuss the external aspect of SDM and put forward applicable solutions to ensure SDM at both patient and physician levels. A standardised validated nine-item SDM questionnaire (patient version SDM-Q-9) was employed. SPSS version 25 was used to perform data analysis. Multiple tests such as Mann-Whitney U and Jonckheere-Terpstra were used. Kendall's Tau coefficient was used for interpretation of the significant relationship among all items of SDM-Q-9 and education. A total of 465 chronically ill patients took part, where majority (63.4%) of patients was above the age of 47. The cohort was dominated by females (67.5%) with 92% of the sample was married. Majority (86.9%) of the patient reported not involved in any decision. During analysis, considerable association was reported between gender and all items of SDM-Q-9, where more men were involved in SDM when compared with women. Our findings did produce significant association between education and SDM-Q-9, which reveals that increase in education can improve the SDM. SDM should not be limited to chronic or emergency in practice. Specific and tailored shared medical DM programmes must be developed for low literacy population implementation. SDM is to be supported at policy and operation levels.

Keywords: Shared-decision making, Cross-sectional assessment, Public healthcare institute, Quetta city, Pakistan

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INTRODUCTION

Shared-decision making (SDM), occasionally called "participatory governance" is the approach in healthcare to ensure that patients have the right to participate effectively in the decision-making (DM) process and the physicians hold themselves responsible to consult with patients (Yishai 2012). The goal of SDM is a collaborative endeavour between patient and doctor to empower patients to be involved as active partners in their health care decisions, especially in chronic diseases or preference-sensitive options where more than one intervention is available (Mincer, Adeogba and Bransford 2013; Veroff, Marr and Wennberg 2013). Patients desire to be involved in DM process and feel the ownership in their own medical decisions (Benbassat, Pilpel and Tidhar 1998), since patients' dissatisfaction arises when they are not being properly informed or involved in their illness and the options for treatment (Coulter and Cleary 2001). Patient participation is not expensive and a useful tool for return on investment and saving billions of dollars each year (Luke, Auraaen and Klazinga 2018).

To participate in medical DM, it is important to ensure that patient-centred education programmes are in place. Patient-centred education is a partnership between healthcare providers, patients and families to enhance information sharing among all members of a treatment team (Siddharthan et al. 2016; Stellefson, Dipnarine and Stopka 2013). Patientcentred education fosters communication (Stellefson, Dipnarine and Stopka 2013), improve drug adherence (Jack et al. 2009; Roberts 2002), reduce hospitalisation time (Roberts 2002), reduce medical costs and have long-term healthcare outcomes (Elwyn et al. 2000). However, some of the patients do not always want to be involved in making decision in regards to their treatment, and leave doctors to take a decision but since 50 years the trend has been changed by using different DM modules, the paternalistic model (relationship between patients and doctors) has been transformed to patient autonomy (HealthTalkOnline 2018). Some of these DM modules are: DECIDE (Guo 2008), Vroom-Yetton-Jago decision model (Field and Andrews 1998), OODA Loop (Wickramasinghe et al. 2009), recognitionprimed decision (RPD) model (Ross et al. 2004), Paired Comparison Analysis (Esposito et al. 2013; Ock et al. 2016; Pile 1964), The Ladder of Inference (Ross 1994), SHARE (Agency for Healthcare Research and Quality 2014), and SDM (Elwyn et al. 2010).

The above mentioned DM models are used in business disciplines; however, SDM model is well-suited in health care system. In order to measure the perceived level of involvement of both patient and physician in treatment DM, the shared decision making questionnaire (SDM-Q) was developed based on Elwyn's model (Elwyn and Charles 2001) and the observing patient involvement (OPTION) scale (Nicolai *et al.* 2012). Originally, the German SDM-Q has 24 questions and following major revisions, questions were reduced to nine and the new instrument was named, the SDM-Q-9. The SDM-Q-9 is translated into several languages (Rodenburg-Vandenbussche *et al.* 2015). This nine-item questionnaire was developed and tested in Germany (Kriston *et al.* 2010). There are two versions of the questionnaire, namely SDM-Q-9 and SDM-Q-Doc. The SDM-Q-9 (patient version) assess the degree to which patients are involved in the process of DM from patient perspective, while SDM-Q-Doc (physician version) measures to which extent physicians involved their patients in DM process from physician perspective.

In addition to SDM model, the World Health Organization (WHO) recognised "responsiveness" as one of three aims of health systems (Üstün *et al.* 2001). The concept of responsiveness in health systems has two dimensions: i) respect for human beings as persons, which involve respecting human dignity, privacy and independence and ii) client orientation, including prompt and well-timed service, adequate facilities, access to social support and freedom to choose providers. To assess the extent of "responsive" in terms

of respect for persons and client orientation, the WHO survey findings from 35 countries shows that United States, Switzerland, Luxembourg, Denmark, Germany, Japan, Canada, Norway, Netherlands and Sweden have the most responsive health systems (Üstün *et al.* 2001).

In the United Kingdom, the MAGIC (Making good decision in collaboration) programme aims to embed SDM in daily clinical practice. In this programme, posters in waiting rooms advise patients to ask these three questions: "What are my options?", "What are the benefits and harms?" and "How likely are these?". Rising patients' self-efficacy will improve their intent to share in DM (Gagnon *et al.* 2010). In the United States, the SDM has become an important element in health policy discussions (Center for Shared Decision Making 2018). To further strengthen this initiative several projects are in pipeline by the Foundation for Informed Medical Decision Making, alike at the Palo Alto Medical Foundation (Frosch *et al.* 2011; Informed Medical Decision Foundation 2018). Likewise, in Canada the SDM initiative has been used in healthcare, and further public plans are underway at various administrative levels (Légaré *et al.* 2011).

In Pakistan, as in many non-Western cultures, decisions about a patient's health care are often made by the family or the doctor (Jafarey and Farooqui 2005; Moazam 2000). A study conducted in Pakistan hospitals reported that majority of residents practiced SDM in their wards (Jameel, Noor and Ayub 2012). However, there is scarcity of information in general. Therefore, the aim of this cross-sectional survey is to employ SDM-Q-9 to measure the SDM process in patients attending the cardiac and medicine ward of tertiary hospital in Quetta, Pakistan.

METHODOLOGY

Study Design and Setting

A questionnaire-based, cross-sectional survey was conducted. Data was collected from patients attending the cardiac and medicine outpatient departments (OPDs) of Sandeman Provincial Hospital (SPH), Quetta, Pakistan. This hospital is the biggest government hospital of Quetta City and provides major healthcare facilities to the general population. Established in 1939 and located in the centre of the city, SPH is a tertiary care, teaching institute. Additionally, being public in nature, SPH is normally the institute of choice for majority of the local residents (Shahzad *et al.* 2018).

Sampling Strategy, Study Population and Inclusion Criteria

All patients suffering from chronic illness and attending the outpatient department of cardiac and medicine department of SPH Quetta were targeted for the study. Patients who were not willing to participate, those cannot read or write Urdu (official language of Pakistan) and immigrants, were excluded from the study. By keeping confidence interval of 95%, 5% margin of error and response distribution of 50%, 392 patients were initially needed for the study. However, keeping a response rate of 20%, final sample of 470 participants were included in the study (Daniel 2010).

Study Instrument

Permission was taken from the developer to use the existing English version of SDM-Q-9 (patient version) (Kriston *et al.* 2010) and was translated in Urdu (National language of Pakistan) by a linguistic expert, the questionnaire was back translated into English by another expert to avoid any discrepancy in the two versions. Face and content validity was established by four physicians and four pharmacists, their opinion were taken into consideration before the pilot study. The questionnaire was subjected to pilot analysis comprising 30 participants. The questionnaire was declared reliable with an acceptable alpha value of 0.8 consequently used for the study.

Data Analysis

SPSS version 21 was used to perform data analysis. Mann-Whitney U test was used for dichotomous variables that reported a significant association between gender and all items of SDM-Q-9. For variables other than dichotomous in nature, the Jonckheere-Terpstra test was used to find the trend of association. In addition, Kendall's Tau coefficient was used for interpretation of the significant relationship that revealed significant, weak association (r < 0.3) among all items of SDM-Q-9 and education.

Ethics Approval

Departmental Ethics Committee at the Faculty of Pharmacy and Health Sciences, University of Balochistan, Quetta approved the study. In addition, permission was also taken from the medical superintendent of SPH. Prior to data collection, the patients were informed about the research initiatives, confidentiality of their responses and their right to withdraw from the study with no penalty or effects on their treatment. Written consent was also taken from the patients.

RESULTS

Demographic Characteristics of the Study Respondents

Data was collected from 465 chronically ill patients with the response rate of 98.93% as shown in Table 1. Majority (63.4%) of patients were above the age of 47. The cohort was dominated by women (314, 67.5%). Ninety-two percent of the respondents were married and majority (404, 86.9%) was not involved in any decision regarding their treatment during their consultation.

Characteristics	Frequency	Percentage
Age (51.62 ± 12.71)		
18–27	5	1.1
28–37	68	14.6
38–47	97	20.9
> 47	295	63.4
Gender		
Man	151	32.5
Woman	314	67.5
Marital status		
Married	429	92.3
Unmarried	36	7.7
Disease state		
Arthritis	70	15.1
Chronic kidney disease	66	14.2
Hypertension	152	32.7
Coronary heart disease	79	17.0
Diabetes mellitus type II	76	16.3
Asthma	22	4.7
Education*		
Un-educated	256	55.1
Religious education	30	6.5
Primary	49	10.5
Matriculation	36	7.7
Intermediate	27	5.8
Undergraduate	38	8.2
Post-graduate	28	6.0
Occupation**		
Unemployed	69	14.8
Housewife	282	60.6
Government employee	58	12.5
Private sector employee	36	7.7
Private business	18	3.9
Monthly income		
Nil	353	75.9
1,000–10,000	6	1.3
10,001–20,000	7	1.5
20,001–30,000	27	5.8
Above 30,000	72	15.5
Locality		
Rural	134	28.8
Urban	331	71.2
Please indicate which decision was made		
No decision was made	404	86.9
About medication	26	5.6
About surgery/ operation	35	7.5

 Table 1: Demographic characteristics of the study's respondents.

Notes: Missing data (* = 1; ** = 2)

Response to SDM-Q-9

As shown in Table 2, majority of patients completely disagreed to all items of SDM-Q-9 with response ranging from 79.6%–84.3%. Only 19 (4.1%) of the patients agreed that their physician asked for the treatment option they will prefer. Additionally, different treatment options were weighed by the physicians and patients in only 20 (4.3%) of the cases. In only 5% of the cases, the patients were informed about different treatment options available for their condition and mutual consensus on how to proceed was agreed by 26 (5.6%) of the patients.

Items in SDM-Q-9	CD		SD		SV	SWD		SWA		SA		CA	
	Ν	%	Ν	%	Ν	%	N	%	Ν	%	Ν	%	
1	387	83.2	8	1.7	2	0.4	23	4.9	9	1.9	36	7.7	
2	392	84.3	9	1.9	13	2.8	13	2.8	12	2.6	26	5.6	
3	392	84.3	15	3.2	10	2.2	10	2.2	15	3.2	23	4.9	
4	386	83.0	14	3.0	8	1.7	19	4.1	11	2.4	27	5.8	
5	370	79.6	13	2.8	9	1.9	27	5.8	18	3.9	28	6.0	
6	386	83.0	17	3.7	13	2.8	18	3.9	12	2.6	19	4.1	
7	385	82.8	15	3.2	10	2.2	18	3.9	17	3.7	20	4.3	
8	388	83.4	15	3.2	10	2.2	15	3.2	15	3.2	22	4.7	
9	388	83.4	16	3.4	7	1.5	16	3.4	12	2.6	26	5.6	

Table 2: Response to SDM-Q-9.

Notes:

1 My doctor made clear that decision needs to be made.

2 My doctor wanted to know exactly how I want to be involved in making the decision.

3 My doctor told me that there are different options for treating my medical condition.

4 My doctor precisely explained the advantages and disadvantages of the treatment options.

5 My doctor helped me understand all the information.

6 My doctor asked me which treatment option I prefer.

7 My doctor and I thoroughly weighed the different treatment options.

8 My doctor and I selected a treatment option together.

9 My doctor and I reached an agreement on how to proceed.

CD = completely disagree; SD = strongly disagree; SWD = somewhat disagree; SWA = somewhat agree; SA= strongly agree; CA= completely agree

Association between SDM and Demographic Characteristics

The association between demographic variables and SDM-Q-9 items was carried out through non-parametric analysis. The Mann-Whitney U test was used for dichotomous variables that reported a significant association between gender and all items of SDM-Q-9. The mean rank interpretation revealed that men were more involved in SDM regarding their treatment when compared with women. However, no significant association was reported between SDM-Q-9 and other dichotomous variables. For variables other than dichotomous in nature, the Jonckheere-Terpstra test was used to find the trend of association. Education was significantly associated with SDM-Q-9. The Kendall's Tau coefficient was used for interpretation of the significant relationship that revealed significant, weak association (r < 0.3) among all items of SDM-Q-9 and education. Hence it is concluded that with an

increase in education, there are possibilities of increase in SDM. In addition, significant association between first six items of SDM-Q-9 and monthly income of patients was also reported. Weak association (r < 0.3) was reported revealing involvement in shared-decision process with an increase in income (Table 3).

Items in	P-value												
SDM-Q-9	Age*	Gender**	Marital status**	Locality**	Disease state*	Education*	Occupation*	Income*					
1	0.881	< 0.01	0.906	0.897	0.234	0.003	0.393	0.015					
2	0.990	< 0.01	0.707	0.562	0.218	0.002	0.393	0.020					
3	0.673	< 0.01	0.774	0.557	0.361	0.001	0.331	0.015					
4	0.974	< 0.01	0.737	0.174	0.213	< 0.01	0.296	0.017					
5	0.818	< 0.01	0.831	0.608	0.123	0.002	0.110	0.008					
6	0.742	0.001	0.584	0.852	0.215	0.004	0.386	0.047					
7	0.484	0.001	0.894	0.385	0.376	0.001	0.485	0.058					
8	0.440	0.001	0.998	0.797	0.546	0.002	0.527	0.068					
9	0.968	0.001	0.656	0.871	0.253	0.007	0.425	0.075					

Table 3	Association	among study	v items	(SDM-0-9)) and	demographic variables
Table J.	Association	amony stud	y items	(30101-0-3)) anu	ucinographic variables

Notes: *Jonckheere-Terpstra test; **Mann-Whitney U test

1 My doctor made clear that decision needs to be made.

2 My doctor wanted to know exactly how I want to be involved in making the decision.

3 My doctor told me that there are different options for treating my medical condition.

4 My doctor precisely explained the advantages and disadvantages of the treatment options.

5 My doctor helped me understand all the information.

6 My doctor asked me which treatment option I prefer.

7 My doctor and I thoroughly weighed the different treatment options.

My doctor and I selected a treatment option together.
 My doctor and I reached an agreement on how to proceed.

DISCUSSION

SDM is a central to shaping effective healthcare system and at patient level; it has the potential to save lives through safety and quality of health services (WHO 2016). Therefore, in this study we examined the effect of SDM on healthcare quality in Quetta among patients using SDM.

However, considering the impact of SDM of healthcare quality, unfortunately, our results showed that majority of cohort was not involved in any decision regarding their treatment during their consultation, which is similar to prior studies, where patient involvement in DM is poor worldwide (Deber *et al.* 2007; McKinstry 2000). But in reality, patients prefer to be offered choices and to be asked their opinions in regards to their disease/treatment (Levinson *et al.* 2005). Research conducted in Malaysia reveals that most of the patients preferred SDM (Ambigapathy, Chia and Ng 2016; Nies *et al.* 2017). In Japan and United States, majority of patients with cancer preferred SDM (Bruera *et al.* 2001; Schaede *et al.* 2017; Singh *et al.* 2010). Therefore, active advocacy at all levels even at patient level (self-advocacy) is necessary to ensure SDM, patient's empowerment (Elwyn, Tilburt and Montori 2013; Shay and Lafata 2014) and healthcare quality.

So the question is, if the governments are committed towards health quality at policy level, then why patients are not or less involved in DM process? Literature has identified three main barriers towards SDM: time constraints (Stacey *et al.* 2006; Whelan *et al.* 2003), lack of applicability due to patient characteristics/preferences (Cabana *et al.* 1999) and the clinical situation (Légaré *et al.* 2008). Therefore, it is imperative that while developing or structuring SDM, it is advised that healthcare providers should keep the individual differences in patient preferences in consideration (Arora and McHorney 2000; Robinson and Thomson 2001) and employ DM models. Research revealed that despite existing barriers there are multiple facilitators to SDM like provider motivation, positive impact on the clinical process and patient outcomes (Légaré *et al.* 2008). Literature review shows that physicians have positive attitudes toward SDM in their clinical practice (Pollard, Bansback and Bryan 2015). That is why SDM and production of SDM training programmes as an effective tool gaining acknowledgement and growing fast in diverse cultures and healthcare setting, in Asia (Légaré *et al.* 2008) and rest of the world (Diouf *et al.* 2016).

Significant association was reported between gender and all items of SDM-Q-9 in our study. More men were involved in SDM regarding their treatment when compared with women. Past research has shown that DM could be influenced by personal and social attributes, such as gender, since women can't share their preferences with doctor as compared to men (Street Jr 1991; Willems et al. 2005). However, gender differences in communication styles between doctors and patients have been hypothesised to impact patient care, but the degree remains unclear (Sandhu et al. 2009). Other researchers believe that both, men and women cautiously process information, think logically about the alternatives, predict results, evaluate the consequences, solve the problems and examine all the decision stages (Sanz de Acedo Lizárraga et al. 2007) and there is no influence of gender on DM (Uzonwanne 2016). In the Asian culture, the DM is often left purely to the doctors or other family members despite of gender differences. In Pakistan still the paternalistic model of DM is a trend. Similarly, literature from Kashmir and Japan reveals that patients are willing to accept what their doctors choose for them and the doctors are pleased with their role as decision-maker (Miyashita et al. 2006; Yousuf et al. 2007). Moreover, researchers from Hong Kong feel that patients and doctors to be more enthusiastic to acknowledge the role of families in DM (Chan 2004).

During statistical analysis, we found a significant association between education and SDM-Q-9, which reveals that increase in education, can improve the SDM. Past research has shown that patients with less educational report less interest in SDM (Kiesler and Auerbach 2006). The importance of education interventions were found effective at increasing the implementation of SDM (Chen et al. 2016). Insufficient health literacy and poor physicianpatient communication are two major healthcare challenges adversely affecting DM and consequently contributing to poor treatment decision, drug adherence and high healthcare costs (Kindig, Panzer and Nielsen-Bohlman 2004). Similarly, there is a strong correlation between quality of physician-patient communication and patient satisfaction and positive health outcomes (Stewart 1995). One of the past studies demonstrated that perceived lack of knowledge is a major barrier to SDM (Belcher et al. 2006) and another study revealed that statistical (numbers) illiteracy hampers SDM (Gaissmaier and Gigerenzer 2008). Previous studies indicated that low literacy skills are strongly associated with lower educational levels (Kim et al. 2001). An economically sound and literate population, properly trained doctors and commitment towards SDM are essential prerequisites for establishing DM in healthcare facilities. Therefore, these findings suggest that health literacy is the cornerstone in effective DM. The health literacy definitions focus on individual skills to obtain process and understand health information and services necessary to make appropriate health decisions (Sørensen et al. 2012). In a nutshell, the SDM model is well-suited and appropriate within real-world

healthcare systems (e.g. nursing, over-the-counter consumer purchases, emergency, chronic illness management and mental illnesses) and thus patients can expect further individualised and personal treatment plans (Tay, Massaro and Vlaev 2017). With all these advances in techniques and tools to encourage patient participation in SDM, challenges still exist in developing tools for patients with lower literacy, poor health knowledge, limited involvement in health decisions and poor health outcomes (McCaffery, Smith and Wolf 2010). SDM practices at clinical level have direct impact over healthcare quality. Therefore, the health care providers and policy makers should strive to strengthen and promote the SDM at primary, secondary and tertiary healthcare settings.

CONCLUSION

As part of healthcare services, SDM should not be limited to chronic, emergency medical situation or where multiple choices are considered. Respect and access to critical information is the right of both doctor and patient. In SDM, the doctor, patient and family are obligated to give one another realistic information about the illness and treatment plan. The policy maker and healthcare providers should put SDM into practice and for the low literacy population, specific and tailored shared medical DM programmes must be developed. For implementation and success of SDM the political and institutional will and support is needed.

FINANCIAL DISCLOSURE AND CONFLICT OF INTEREST

No funding was received for the study. The authors have no conflict of interest to declare.

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