# Tehran University of Medical Sciences

#### **Nursing Practice Today**

2021; Volume 8, No 3, pp. 179-193



#### **Review Article**

### Impact of using question prompt list on shared decision-making in the cancer patient: A systematic review

Reza Negarandeh<sup>1</sup>, Zahra Yazdani<sup>2</sup>\*, Sarina Ramtin<sup>2</sup>, Leila Janani<sup>3</sup>

<sup>1</sup>Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran <sup>2</sup>Department of Community Health and Geriatric Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

<sup>3</sup>Department of Biostatistics, School of Public Health, Iran University of Medical Sciences, Tehran, Iran

#### ARTICLE INFO

Received 15 January 2021 Accepted 16 February 2021

Available online at: http://npt.tums.ac.ir

#### Key words:

question prompt list; shared decision making; cancer participation; Iran

#### \*Corresponding Author:

Zahra Yazdani, Department of Community Health and Geriatric Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran. E-mail: yazdani.zahra1394@gmail.com

10.18502/npt.v8i3.5933

#### ABSTRACT

Background & Aim: Shared decision making belongs to the continuum between the two decision-making paradigms of the paternalistic perspective and the client's complete independence. Various interventions, including the Question Prompt List have been developed to facilitate patients' participation in counseling. This study aims to investigate the effects of question prompt list on shared decision making among cancer patients.

Methods & Materials: For this study, the researchers performed a systematic review of the manuscripts available in Embase, PubMed, Scopus, and Web of Science databases which were published until January 2021. And then, the eligible studies investigating the effect of question prompt list on shared decision making were included in the study. The quality of the studies was assessed using the Cochrane risk of bias tool.

**Results:** Two eligible papers were included in the study, and it was reported that question prompt list was provided before the patients' consultation with the physician. Both studies have used OPTION 12 to measure shared decision making. The two articles reported that patient communication aid and question prompt list had no significant effect on improving shared decision making through OPTION 12.

**Conclusion:** The findings of this systematic review could not confirm the impact of using question prompt list on shared decision making. more preliminary studies are needed to answer the question expressed by this systematic review study.

#### Introduction

Decision-making, in chronic diseases like cancer, is influenced by several factors, including the treatments' efficacy and safety, the cost, and the desirability of the treatments. Shared Decision Making (SDM) is a means to keep a balance between these factors considering patients' values and preferences and the healthcare providers' recommendations (1). SDM belongs to the decision-making spectrum between paternalistic perspective and the client's complete independence (2).It

characterized by the following four features: 1) there are at least two people involved in the process (the client and healthcare providers); 2) some information is shared between the client and the healthcare team; 3) preferences are expressed, and finally 4) both parties reach an agreement (3). In fact, SDM is not just about providing evidencebased information and expressing advantages and drawbacks of the treatments; it means that patients' preferences and values must be taken into account while choosing the appropriate treatment. SDM

Please cite this article as: Negarandeh R, Yazdani Z, Ramtin S, Janani L. Impact of using question prompt list on shared decision-making in the cancer patient: A systematic review. Nursing Practice Today. 2021; 8(3):179-193



can lead to the strengthening of patients' responsibility for care and treatment, promotion of adherence to treatment. reduction of medical errors and treatment costs, improvement of patients' self-control, enhancement of the quality of care, improvement of treatment outcomes, and improvement of patients' satisfaction. understanding and confidence in decision making. It can also reflect patient-centered care (2,4). Various interventions, including QPL, have been developed to facilitate patients' participation in consultation (5). Although the value of patient decision aids (of which the OPL is one form of them) is known in healthcare services, they have yet to be used in routine care (4).

QPL refers to a method for asking questions which are based on evidence and includes an organized list of questions that the patients may express to healthcare providers (6,7). It is also designed in order to help patients obtain the information pertinent to their personal needs at their own level (6). The purpose of the QPL is to support clients to obtain information according to their diagnosis and treatment, to express concerns, to enhance the relationship between the client and the healthcare team, to promote participation, and to potentially increase SDM during counseling sessions. If the data show that QPL is effective, it can be considered as a useful tool for asking questions and promoting participation (8). Although several preliminary studies have been conducted on the impact of QPL, there are only limited studies investigating the impact of QPL on SDM. Previous studies have examined the effect of QPL on a variety of variables. For example, Lim et al. mentioned the reduction of the level of anxiety (9), Shirai et al. assessed the number of questions asked during the consultation (10), and Kidd et al. mentioned an increase in self-confidence to ask questions (11). Various review studies have been conducted to help patients in decision-making (7,12–14). Dimoska et al. examined the effect of the QPL on the number of questions asked by cancer patients (7). Besides, Henselmans et al. conducted a systematic review study to

investigate the interventions that affect the cancer patients' participation in consultations; they also included QPL in the list of interventions to be reviewed (13). Spiegle et al. have also reported interventions that help cancer patients to make decisions (12). Besides, Van der Meulen et al. examined interventions that lead to recall medical information and claimed that QPL is one of those interventions (14). Reviewing these studies showed that only a few studies have examined the effect of OPL on SDM and they have not answered the question posed within the present study "does QPL affect SDM in cancer patients". Therefore, this systematic review aims to collect and integrate data from previous studies and achieve the results with higher-level evidence.

#### Methods

#### Protocol and registration

The study protocol is registered in PROSPERO (no. CRD42020119774) and is available on:

https://www.crd.york.ac.uk/prospero/display record.php?ID=CRD42020119774.

#### Ethics approval

This study has been approved by the ethics committee of Tehran University of Medical Sciences with a number of IR.TUMS.VCR.REC.1398.174.

#### Eligibility criteria

Based on PICO (Population, Intervention, Comparison, and Outcome), the present study sought to investigate whether the effects of QPL (Intervention) on SDM (Outcome) among cancer patients (Population) as compared to routine care (Comparison).

Randomized Controlled Trial and Non-Randomized Controlled Trial papers were included in the study. QPL intervention was used alone or in combination with other interventions, and shared decision making had been measured. These articles were peer-reviewed either in Persian or English,

which were published before 27 January 2021. The samples included people 18 years old and over who were diagnosed with cancer (any type of cancer and at any stage). The following exclusion criteria were taken into account for the present systematic review study: studies that did not belong to randomized or non-randomized clinical trials, studies that were not published in peer-reviewed journals, and studies whose samples patients were under 18 years of age.

#### Information sources

Given that the researchers needed to become familiar with previous researches and set the necessary criteria, a preliminary review with a comprehensive strategy formula was performed using the following expressions: "shared decision making," "Question Prompt List," and "cancer." The Persian articles were searched on SID, Irandoc, Magiran, and Google Scholar databases using Persian equivalents of the English keywords. The English articles were searched from Embase. PubMed. Scopus. and Web of Science databases using the keywords. following appropriate The paragraph contains the search syntax for the Embase database. Two researchers (ZY and RN) wrote the search strategy in terms of **PICO** (Population, Intervention. Comparison, and Outcome).

#### Search strategy

((cancer OR oncology OR neoplas\* OR malignan\*) AND (question prompt list OR question prompt sheet OR prompt list OR prompt sheet) AND (patient participation OR consumer participation OR patient involvement OR consumer involvement OR patient engagement OR consumer engagement))

The most effective terms which helped identify the related studies included "question prompt list," "question prompt sheet," and "patient participation." These terms were used to search for related articles (gray literature) on Google, Google Scholar,

and the clinical trials which are registered in other countries on the World Health Organization website (15). Moreover, the snowballing technique was used i.e., the references and citation searches in similar studies were examined in terms of competency criteria. PRISMA flow diagram was also used to report the text search and review process.

#### Study selection

Two researchers (SR & ZY) separately screened the titles and abstracts of the searched articles. And then, they screened the entire content of the selected articles. If there was a disagreement at any stage, the two researchers would argue with each other; and in case the disagreement was not resolved, the third researcher (RN) would be considered as the consultant.

#### Data collection process

The two researchers (ZY & SR) separately extracted the data from the articles based on the data extraction form and discussed over any disagreements; if necessary, the help of the third researcher (RN) was sought. To extract the data, the researchers used a checklist consisting of authors' name, the title of the article, year of publication, country, language, type, and article, quality of the participants' characteristics (number, age, and gender), measurement tools used for SDM variable, interventions, outcome (s), mean, standard deviation, P-value and effect size. If any part of the data was reported incomplete or it was protocol study, we contacted corresponding authors to seek the missing information.

#### Assessment of methodological quality

The quality of the studies was assessed using the Cochrane risk of bias tool. This tool examines the bias in randomized clinical trials (RCTs) as a judgment (high, low, or unclear) for individual elements from five domains (selection, performance, attrition,

reporting, and other). The studies were classified into three categories of good, fair, and poor in terms of quality. Good quality studies have low bias scores for all five domains. If any study reported high bias for one of the dimensions or uncertain bias for two or more dimensions, and assessment revealed that it was unlikely to have biased the outcome, it was considered a fair-quality study. Otherwise, the study was considered a poor-quality study. The quality of the studies was assessed separately by two researchers & SR). Besides, the probable disagreements were resolved through discussion and/or using the third researcher's views (RN).

#### Synthesis of results

The narrative synthesis approach was used to synthesize the findings of the studies. The results were discussed and the summary of the studies was reported narratively.

#### Results

#### Study selection

Figure 1 shows the search results. 342 documents were obtained using the search strategy in electronic resources (Embase: 76, PubMed: 71, Scopus: 51, and Web of Science: 144), but 97 were duplicated and deleted.

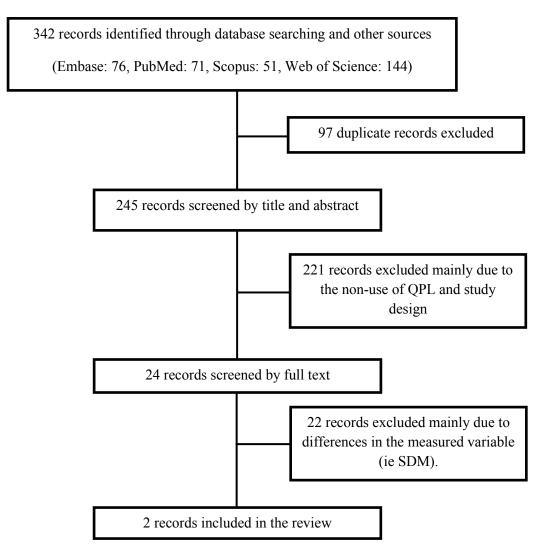


Figure 1. Study flow diagram

The titles and abstracts of 245 documents were screened in terms of criteria; 24 articles were eligible for the full-text screening (Table

1) and only 2 articles were eligible in terms of the objectives and criteria of the present study (Table 2) (16,17). Table 1 provides a brief description of the 22 articles which were excluded because these studies mainly investigated different variables other than SDM. In the gray literature, only one study related to the objectives of the present research was found, which is still under study

by some researchers who are also involved in the current review study, and the results have not been published yet. This clinical trial is registered in the Iranian Registry of Clinical Trials (no. IRCT20190626044032N1), and its protocol is published (18).

Table1. 22 articles screened in the title and abstract stage

Number	First author	Title	Publication year	Intervention(s)	Outcome variable(s)	Reasons for excluding
1	Yuki Shirai (51)	Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial	2011	QPL	Usefulness of the QPL, satisfaction with the consultation, Number and contents of the questions asked	SDM hadn't been measured.
2	Josephine M. Clayton (52)	Physician endorsement alone may not enhance question- asking by advanced cancer patients during consultations about palliative care	2012	QPL	Question asking, information preference, preference for involvement in decision making, anxiety	SDM hadn't been measured.
3	Rachel A. Rodenbach (53)	Promoting End-of-Life Discussions in Advanced Cancer: Effects of Patient Coaching and Question Prompt Lists	2017	QPL and coaching patients about how to ask question and express concerns	Effects of intervention on topics brought up, topics of interest identified during coaching session, topics of interest from coaching session brought up during office visit	SDM hadn't been measured.
4	RF Brown (54)	Promoting patient participation and shortening cancer consultations: a randomised trial	2001	QPL and physician endorsement of the QPL	Question asking, consultation length, information needs, recall information, anxiety, satisfaction	SDM hadn't been measured.
5	R Brown (55)	Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking	1999	QPL and coaching patients	Question asking, anxiety, patient satisfaction, psychological adjustment to cancer	SDM hadn't been measured.
6	Josephine M. Clayton (56)	Randomized Controlled Trial of a Prompt List to Help Advanced Cancer Patients and Their Caregivers to Ask Questions About Prognosis and End-of-Life Care	2007	QPL and physician endorsement of the QPL	Question asking, topics discussed, consultation length, information needs, anxiety, satisfaction, participants' views of the QPL	SDM hadn't been measured.
7	Susan Eggly (57)	Randomized trial of a question prompt list to increase patient active participation during interactions with black patients and their oncologists	2017	QPL and coaching patients	Patient perceptions of the intervention, interaction length, patient active participation, oncologist communication, patient role in treatment decision, patient trust in the oncologist	SDM hadn't been measured.
8	I. Henselmans (58)	A randomized controlled trial of a skills training for oncologists and a communication aid for patients to stimulate shared decision making about palliative systemic treatment (CHOICE): study protocol	2018	Oncologist training about SDM, communication aid (include patient education about SDM, QPL, a value clarification exercise)	SDM, perceived communication efficacy by patients, satisfaction with communication, perceived oncologist empathy, preferred/perceived	This was a study protocol and results had not been published.

					decisional role, patient- reported SDM, decision evaluation, trust in the oncologist, attitudes towards striving for quantity (length) or quality of life, quality of life, anxiety, fighting spirit, helplessness/hopelessne ss,	
9	Alessandro Bottacini (59)	The involvement of early stage breast cancer patients during oncology consultations in Italy: a multi-centred, randomized controlled trial of a question prompt sheet versus question listing	2017	QPL, QL (patient self- generated list of questions)	Question asking, satisfaction with information, satisfaction with the decision, anxiety	SDM hadn't been measured.
10	E. M. A. Smets (20)	Addressing patients' information needs: a first evaluation of a question prompt sheet in the pretreatment consultation for patients with esophageal cancer	2012	QPL	Total number of questions asked, consultation length, patients' satisfaction, easiness to ask questions	SDM hadn't been measured.
11	Kim Brandes (60)	Advanced cancer patients' and caregivers' use of a Question Prompt List	2014	QPL	Usefulness and usage of the QPL, question asking, content of question asked	SDM hadn't been measured.
12	Eduardo Bruera (19)	Breast Cancer Patient Perception of the Helpfulness of a Prompt Sheet Versus a General Information Sheet During Outpatient Consultation: A Randomized, Controlled Trial	2003	QPL and general information sheet	Patient rating of helpfulness of the information package and satisfaction, consultation length, number of questions asked	SDM hadn't been measured.
13	Phyllis Butow (61)	Cancer Consultation Preparation Package: Changing Patients but Not Physicians Is Not Enough	2004	For intervention group: Cancer Consultation Preparation Package (CCPP= QPL, booklets on clinical decision making and patient rights, and an introduction to the clinic) For control group: booklet contained only the introduction to the clinic	Anxiety, depression, Information and involvement preferences, patient and physician perception of information provided and role in decision making, patient satisfaction with the booklet or CCPP, patient satisfaction with the consultation, information-seeking behavior, patient and physician satisfaction with the decision- making process.	SDM hadn't been measured.
14	D. Langbecker (62)	Development and piloting of a brain tumor-specific question prompt list	2012	QPL, standard brochure about brain tumor	Acceptability of the QPL or standard brochure, feasibility of outcome assessment	SDM hadn't been measured.
15	Adam Walczak (63)	Discussing prognosis and end- of-life care in the final year of life: a randomized controlled trial of a nurse-led communication support programme for patients and caregivers	2014	Two nurses have been trained to deliver the intervention, which consists of two sessions: (1) a face-to-face Meeting and (2) a telephone booster session. Face-to-face meetings include a QPL designed for patients and caregivers	Patients' and caregivers' participation in medical consultations, their self-efficacy in medical encounters, quality-of-life, end-of-life care receipt and quality-of death indicators.	This was a study protocol and results had not been published.

16	Ronald M. Epstein (64)	Effect of a Patient-Centered Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilization in Advanced Cancer The VOICE Randomized Clinical Trial	2017	Oncologists communication training, QPL, coaching patients about communication	Patient-centered communication, patient-physician relationship, shared understanding of prognosis, QOL, aggressive treatments and hospice use in the last 30 days of life	SDM hadn't been measured.
17	Julia. C. M. van Weert (65)	Effects of communication skills training and a Question Prompt Sheet to improve communication with older cancer patients: A randomized controlled trial	2011	For nurses: web- enabled video- feedback, communication skills training, follow-up meeting. For patients: booklet including QPL	Information recall, quality of communication, the number and content of questions asked	SDM hadn't been measured.
18	Adam Walczak (66)	Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers	2017	Communication Support Program including nursing communication skills training, QPL, physician endorsement of the QPL	Communication behavior in recorded consultation (impact of the intervention, other predictors of consultation behaviors, consultation length), communication self- efficacy, preferences for information and decision-making, quality of life, satisfaction with the intervention	SDM hadn't been measured.
19	S. Aranda (67)	Impact of a novel nurse-led prechemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs: results from a randomised, controlled trial	2012	ChemoEd including 3 group interventions: intervention 1 included DVD, QPL, self-care information, education consultation ≥ 24 h before first treatment, intervention 2 included telephone follow-up 48 h after first treatment, intervention 3 included a face-to-face review immediately before second treatment	Patient distress, treatment-related concerns, and the prevalence and severity of and bother caused by six chemotherapy side- effects	SDM hadn't been measured.
20	Claudia Goss (68)	INvolvement of breast CAncer patients during oncological consultations: a multicentre randomised controlled trial—the INCA study protocol	2013	QPS	The number and content of questions asked, the unmet information needs, ability to cope with the illness, patient involvement, satisfaction with decisions made, recalling and understanding of information, consultation atmosphere, perceived patient—doctor relationship, perceived role preference of the patient, consultation length	This was a study protocol and results about SDM had not been published.

21	Martin H N Tattersall (69)	Parallel multicentre randomised trial of a clinical trial question prompt list in patients considering participation in phase 3 cancer treatment trials	2017	QPL	Quality of Informed Consent (QuIC), anxiety, patient satisfaction with decision, clinical satisfaction with the informed consent process and with decision making process	SDM hadn't been measured.
22	Chiara Buizza (70)	Does being accompanied make a difference in communication during breast cancer consultations? Results from a multi-centered randomized controlled trial	2020	QPL and QL (question listing)	Satisfaction with decisions, ability to cope with the illness, shared decision making, depression, mental and physical disorders, preference for participation	The effect of QPL and QL on SDM had been measured but there was no control group with routine care to compare.

#### Study characteristics

Both eligible studies were published in English. The average age range between the two studies was 61.8 years. The study by Henselmans et al. was RCT, and its quality was assessed as fair quality. However, Amundsen et al.'s study quasi-experimental, and its quality was assessed poorly (Table 2).

 Table 2. Characteristics of two eligible articles

hor	Year	Country	Language	Type	Quality	Total sample size	au)	Gender (%)		و	Tr. C	
First author							Age (Mean)	Male	Female	Measure	Type of intervention	Outcomes
Hense lmans et al. (16)	2019	Netherland	English	RCT	Fair	For OPTION 12 and 4SDM n=187 For SDM-Q- 9=163	63.6	51	49	OPTI ON 12 + SDM- Q-9	Combined: Oncologist SDM training+Patient communication aid (education about SDM, QPL, and value clarification methods (VCMs))	Observed SDM, patient- reported SDM, satisfaction, decisional conflict, quality of life, consultation length, the decision made
Amun dsen et al. (17)	2018	Norway	English	non- RCT	Poor	93	60	49.5	50.5	OPTI ON 12	Combined: QPL + Consultation audio record	Number and content of questions asked, observed SDM, anxiety/depres sion, quality of life

## Review the effectiveness of QPL on SDM

Participants of Henselmans et al.'s study (16) included oncologists and the patients. The oncologists were divided into two groups: the control group (receiving routine care) and the intervention group (receiving

training about SDM). The patients were allocated into 4 groups: 1) the group that did not receive PCA (Patient Communication Aid) but the doctors were trained, 2) the group that received PCA but the doctors were not trained, 3) the group that received PCA, and their doctors were trained about SDM, and 4) the group that did not receive PCA and their doctors were not trained

either. In this study, PCA was a paper brochure containing QPL, education about SDM, and Value Clarification Methods (VCMs). QPL included organized questions that the patients were allowed to ask their physician. VCMs also included questions about identifying the values in a way that the patients could share their values preferences with their physicians answering these questions. In this study, PCA was provided to the patients prior to the consultation. SDM was measured from the perspective of both the doctors and the patients. The 12-item Observing Patient Involvement scale (OPTION12) and the four-step SDM instrument (4SDM) was used to measure the observed-SDM, which was the primary outcome of this study. It is necessary to record counseling sessions visually or auditory to use these two tools.

Given the physicians' opinions during the consultation, their conversation with the patient is coded, and SDM is measured by analyzing these codes. As a matter of fact, OPTION 12 is an objective tool that assesses the healthcare team in terms of whether they involve patients in decisions or not; however, it does not evaluate the patients' perception of this involvement. Therefore, the nine-item Shared Decision-Making Ouestionnaire (SDM-Q-9) was also used to SDM from measure the patients' perspectives in this study. SDM-Q-9 is a self-reporting tool that measures SDM based on the patients' perception during the consultations. OPTION 12 and SDM-O-9, if applied together, can complement each other and give an accurate assessment of SDM in the study. The results measured by OPTION 12 in this study were as follows: oncologist training was able to improve SDM (Cohen's d = 1.12) (mean (SD) OPTION 12 score=49.4±14.19) in group 1; PCA failed to improve SDM in group 2; the combination of the interventions improved (Cohen's d=1.21) (mean (SD) OPTION 12 score=49.83±12.8) in group 3, but the effect size was almost equal between group 1 and group 3. In other words, adding PCA, which includes QPL, had not improved SDM.

On the other hand, the results measured by SDM-Q-9 are reported as follows: SDM did not improve in group 2; the intervention was able to improve SDM (Cohen's d=0.73) in group 1; SDM was improved, but the effect size did not change much (Cohen's d=0.83) in group 3. In other words, PCA had fewer effects compared to oncologist training. Overall, the reported results indicated that SDM which was measured by OPTION 12 and SDM-Q-9, was influenced by oncologist training, not PCA.

Unlike Henselmans et al.'s study, Amundsen et al. (17) only investigated the patients who were allocated into three groups: 1) control group, 2) the group that only received QPL (QPL group), and 3) the group that received CAR (consultation audio recording) along with OPL (combined group). The sampling was done at different times for the three groups, i.e., the control group (April to June 2014), the QPL group (April to June 2015), and the combined group (November to January 2015/2016). In this study, only OPTION 12 was used to measure SDM. The data were collected from 93 patients in this study (control group=31, QPL group = 30, and combined group=32). In addition, the mean score of OPTION 12 was 12.1 (SD=7.9) in the control group and 14.8 (SD=9.2) in the other two groups (QPL and combined group). The statistical tests did not report a significant difference (P=0.16). In this study, in addition to measuring SDM, the researchers also measured the number of questions that were asked by the patients. It is interesting to note that the average number of questions that were asked by the patients was 23 in the QPL and combined groups and 17 in the control group. The statistical tests did not report any significant differences between the two groups (P < 0.070).

In both studies, QPL was used along with another intervention, and the reported findings were the results of a combination of the effects of several interventions. It should be noted that QPL was provided prior to visiting the doctor. Besides, OPTION 12 was used as a measurement tool in both of these two papers. The main differences

between these two articles were the type of intervention and the tools which were used to measure SDM. Both papers reported that PCA and QPL had no significant effect on improving SDM which was measured by OPTION 12.

#### Discussion

The findings of this systematic review showed that little available evidence could not predict the impact of using OPL on the promotion of SDM. In recent years, researchers have paid more attention to patients' participation improving decision-making. They have applied a variety of interventions such as QPL to improve SDM. Researchers have already examined the effect of OPL on different variables such as total question asking (19), question-asking by content (20), information is given (21), knowledge recall, anxiety, patient satisfaction, and consultation length (22); however, the results of this systematic review showed that they had paid only a little attention to the impact of QPL on SDM.

The study hypothesis was developed based on the fact that some studies have confirmed that QPL can increase patients' asking questions (20); therefore, the authors concluded that if QPL can increase question asking during consultations, it may also be able to promote SDM. However, the combination of the results of the two studies which were conducted in this field could not confirm this hypothesis. Henselmans et al. reported that physician training alone and in combination with PCA had an impact on SDM, which was measured by OPTION 12. Contrary to their study hypothesis, the results indicated that PCA had no effect on SDM by itself, and also, it could not increase the effect size along with the oncologist training. Similarly, the intervention which was used in Amundsen et al.'s study could not improve the mean scores of OPTION 12.

Both studies were conducted in Western countries, while the pattern of participation is not the same in different cultures (23).

Willingness to participate is one of the most important determining factors in SDM that can vary from one culture to another. Aminaie et al. conducted a study in Iran and reported that 90% of women in the early stages of breast cancer prefer to leave the responsibility for treatment decisions to the doctors (2). In other Middle Eastern countries such as Jordan, it has been reported that 50% of the patients prefer a passive role in their treatment process (24). However, studies that were conducted outside the Middle East region have shown that breast cancer patients prefer to be actively involved in treatment decisions (25). One study was conducted on 84 lung cancer patients in stages  $\overline{I}$  and  $\overline{II}$  in the Netherlands. The findings indicated that 85% of the patients preferred participatory decision-making, and only 12% of them would leave all the decisions to the doctor (26). The nature and severity of the disease are the two factors influencing the patients' preference for participation. Cancer can be considered as a life-threatening factor; therefore, patients may trust their doctors as a person who has the most required information (2). This can justify the results of this systematic review. On the other hand, it is necessary to conduct more preliminary studies within different cultures as well.

of information or patients' misinformation (27) and lack of adequate education to the patients are other obstacles of SDM. Accordingly, Watanabe reported that Japanese patients believed that they had to make decisions even without sufficient information (28). In some countries such as Japan and Saudi Arabia, it is considered announce "cancer" undesirable to diagnosis to the patients(29,30). majority of the physicians (75%), 249 physicians, who participated in Mobeireek et al.'s study study in Saudi Arabia would prefer to report the diagnosis of serious illnesses such as cancer to the patients' family members rather than the patients themselves(31). In another qualitative study on eight cancer patients in Iran, Beyraghi et al. reported that although all patients believed that they have the right to be

informed of the truth about their health status, they tended to leave the entire decisions regarding their treatment to the doctor because they claimed that they have complete faith and trust in their doctor. Most of the doctors in this study believed that it is wrong to directly tell the patients about the diagnosis of "cancer" (32).

Several studies reported the following barriers to SDM: time constraints (33), patients' anxiety and lack of self-efficacy (34), lack of a consistent doctor or nurse who provides care (35), unfavorable environmental conditions in healthcare centers such as noisy environment (36), lack of privacy (37), specialization and having several doctors (38), cognitive impairments such as dementia (39), low level of literacy (35), the nature of the disease (such as infectious diseases, alcoholism, and life threatening diseases) (40-42), physical impairments such as hearing and visual impairments (35,36), characteristics of the decisions (for example, decisions about sexual issues that are considered as a stigma in some cultures (43) or decisions about endof-life (44)),lack of appropriate opportunities and time to adapt to and accept the diagnosis (45), power imbalance in the relationship between the patient and the healthcare provider (46), and patients' belief that SDM shows them as "difficult" which leads to reduce quality of care and less attention from the healthcare providers (47). Some patients believe that asking questions is a sign of distrust or disrespect for healthcare providers; on the contrary, some other patients consider asking questions as a facilitator for SDM (40,47).

Moreover, the following characteristics of healthcare personnel can also be considered as the barriers of SDM: their authoritarian perspective (46), lack of attention to and respect for the patients' concerns (48), negative verbal or non-verbal behavior (49), and using of medical words (37) in such a way that patients have expressed the doctor speaks another language (46) or beyond their comprehension (50).

It is perceived that time constraints in counseling sessions may lead to decline information received and question asking (47,49). Although the asking question does not mean SDM, it is considered as one of the essential and inseparable parts of SDM (39). It has been reported that patients forget their questions during the consultation and remember them right after consultations. It is also concluded that patients may not know how to express their questions. Patients have stated that preparing questions or prompting questions during the consultation, making notes, and searching the Internet before the consultation can lead to greater participation (33).

Health care providers tend to involve the caregiving and treatment patients in processes, but this process implementation is time-consuming (27). Therefore, when the length of meeting with healthcare providers is crunch time, and there is a wide range of information to share with the patients, QPL can make this time more efficient by guiding patients in choosing the right questions regarding decision making. On the other hand, in some situations, such as making decisions about cancer treatment where there is no BEST option, decisions are considered high quality based on the latest scientific evidence and patients' values about the consequences (4). In order to identify patients' values and preferences, they must be involved in the decision-making process. There are a number of effective approaches, including QPL, which can help to involve patients in making decisions. As a matter of fact, QPL could potentially facilitate SDM by identifying the questions that clients must know to make a decision; at the same time, it helps healthcare providers to understand patients' values and preferences about the treatments and the related appropriate information for their condition.

#### Limitation

Although this study sought to identify studies related to the use of systematic text search and gray text search without time constraints, some studies might have been missed.

#### Conclusion

According to the accepted ethical principles, the patient is considered as an autonomous agent, and it is believed that the patient must decide for his/her own future(30). The findings of this systematic review could not confirm the impact of using QPL on SDM. Nevertheless, given the small number of studies that were found in this field, more preliminary studies are needed to answer the question expressed by this systematic review study. It is also suggested that subsequent preliminary studies investigate the patients' preferences in decision making and their understanding of SDM be measured using some scales such as SDM-Q-9 as the primary outcomes.

#### Acknowledgments

The authors would like to thank the Tehran University of Medical Sciences for financial support (Grant number: 41787).

#### **Conflict of interests**

The authors declared no potential conflicts of interest for the research, authorship, and/or publication of this article.

#### References

- 1. Khammarnia M, Eskandari M, AlinezhadeRanjbar A, Ansari-Moghadam A, Peyvand M. Participation rate of cancer patients in treatment decisions: A cross sectional study. J Heal Lit. 2017;2(3):156–63.
- 2. Aminaie N, Lehto RH, Negarandeh R. Iranian women's decision making: Preferred roles, experienced involvement, and decisional conflict when undergoing surgery for early-stage breast cancer. Clin J Oncol Nurs. 2019;23(5):529–36.
- 3. Bélanger E, Rodríguez C, Groleau D. Shared decision-making in palliative care: A systematic mixed studies review using narrative synthesis. Palliat Med. 2011;25(3):242–61.
- 4. Stacey D, Samant R, Bennett C. Decision making in oncology: A review of patient

- decision aids to support patient participation. CA Cancer J Clin. 2008;58(5):293–304.
- 5. Miller N, Rogers SN. A review of question prompt lists used in the oncology setting with comparison to the Patient Concerns Inventory. European journal of cancer care. 2018 Jan;27(1):e12489.
- 6. Clayton J, Butow P, Tattersall M, Chye R, Noel M, Davis JM, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. Br J Cancer. 2003;89(11):2069-77.
- 7. Dimoska A, Tattersall MHN, Butow PN, Shepherd H, Kinnersley P. Can a "prompt list" empower cancer patients to ask relevant questions? Cancer. 2008;113(2):225–37.
- 8. Sansoni JE, Grootemaat P, Duncan C. Question prompt lists in health consultations: a review. Patient Educ Couns. 2015;98(12):1454–64.
- 9. Lim L, Chow P, Wong C-Y, Chung A, Chan Y-H, Wong W-K, et al. Doctor–patient communication, knowledge, and question prompt lists in reducing preoperative anxiety–A randomized control study. Asian J Surg. 2011;34(4):175–80.
- 10. Shirai Y, Fujimori M, Ogawa A, Yamada Y, Nishiwaki Y, Ohtsu A, Uchitomi Y. Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial. Psycho-Oncology. 2012 Jul;21(7):706-13.
- 11. Kidd J, Marteau TM, Robinson S, Ukoumunne OC, Tydeman C. Promoting patient participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. Patient Educ Couns. 2004;52(1):107–12.
- 12. Spiegle G, Al-Sukhni E, Schmocker S, Gagliardi AR, Victor JC, Baxter NN, et al. Patient decision aids for cancer treatment: are there any alternatives? Cancer. 2013;119(1):189–200.
- 13. Henselmans I, de Haes HCJM, Smets EMA. Enhancing patient participation in oncology consultations: a best evidence synthesis of patient-targeted interventions. Psycho-Oncology. 2013;22(5):961–77.
- 14. van der Meulen N, Jansen J, van Dulmen S, Bensing J, van Weert J. Interventions to improve recall of medical information in cancer patients: A systematic review of the literature. Psycho-Oncology J Psychol Soc Behav Dimens Cancer. 2008;17(9):857–68.

- 15. International Clinical Trials Registry Platform (ICTRP) [Internet]. World Health Organization. [cited 2020 Jun 8]. Available from:
- https://www.who.int/ictrp/network/primary/en/
- 16. Henselmans I, van Laarhoven HWM, van Maarschalkerweerd P, de Haes HCJM, Dijkgraaf MGW, Sommeijer DW, et al. Effect of a skills training for oncologists and a patient communication aid on shared decision making about palliative systemic treatment: A randomized clinical trial. Oncologist [Internet]. 2019 Nov;25(3):e578–88. Available from: http://www.embase.com/search/results?subactio n=viewrecord&from=export&id=L2003783570
- 17. Amundsen A, Bergvik S, Butow P, Tattersall MHN, Sørlie T, Nordøy T. Supporting doctor-patient communication: Providing a question prompt list and audio recording of the consultation as communication aids to outpatients in a cancer clinic. Patient Educ Couns. 2018;101(9):1594–600.
- 18. Negarandeh R, Yazdani Z, Lehto R, Lashkari M. The effect of using the question prompt list on shared decision making, self-efficacy in decision making, and preferences for participation among women with breast cancer: A study protocol. Int J Cancer Manag. 2020;13(8):e103873.
- 19. Bruera E, Sweeney C, Willey J, Palmer JL, Tolley S, Rosales M, et al. Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomized, controlled trial. J Pain Symptom Manage. 2003;25(5):412–9.
- 20. Smets EMA, van Heijl M, van Wijngaarden AKS, Henselmans I, van Berge Henegouwen MI. Addressing patients' information needs: a first evaluation of a question prompt sheet in the pretreatment consultation for patients with esophageal cancer. Dis Esophagus. 2012 Aug;25(6):512–9.
- 21. Shepherd HL, Barratt A, Trevena LJ, McGeechan K, Carey K, Epstein RM, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. Patient Educ Couns. 2011;84(3):379–85.
- 22. Brown RF, Butow PN, Dunn SM, Tattersall MHN. Promoting patient participation and shortening cancer consultations: A randomised trial. Br J Cancer. 2001;85(9):1273.

  23. Obeidat RF, Homish GG, Lally RM.
- 23. Obeidat RF, Homish GG, Lally RM. Shared decision making among individuals with

- cancer in non-Western cultures: A literature review. Oncol Nurs Forum. 2013 Sep;40(5):454-63
- 24. Obeidat R, Khrais HI. Jordanian physicians' attitudes toward disclosure of cancer information and patient participation in treatment decision-making. Asia-Pac J Oncol Nurs. 2016;3(3):281-88.
- 25. Hamelinck VC, Bastiaannet E, Pieterse AH, van de Velde CJH, Liefers G-J, Stiggelbout AM. Preferred and perceived participation of younger and older patients in decision making about treatment for early breast cancer: a prospective study. Clin Breast Cancer. 2018;18(2):e245–53.
- 26. Mokhles S, Nuyttens J, de Mol M, Aerts J, Maat A, Birim Ö, et al. Treatment selection of early stage non-small cell lung cancer: the role of the patient in clinical decision making. BMC Cancer. 2018;18(1):79.
- 27. Charles C, Gafni A, Whelan T. Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. Heal Expect. 2004;7(4):338–48.
- 28. Watanabe Y, Takahashi M, Kai I. Japanese cancer patient participation in and satisfaction with treatment-related decision-making: A qualitative study. BMC Public Health. 2008;8(1):77.
- 29. Mitchell JL. Cross-cultural issues in the disclosure of cancer. Cancer Pract. 1998;6(3):153–60.
- 30. Younge D, Moreau P, Ezzat A, Gray A. Communicating with cancer patients in Saudi Arabia. Ann N Y Acad Sci. 1997;809:309–16.
- 31. Mobeireek AF, Al-Kassimi FA, Al-Majid SA, Al-Shimemry A. Communication with the seriously ill: physicians' attitudes in Saudi Arabia. J Med Ethics. 1996;22(5):282–5.
- 32. Beyraghi N, Mottaghipour Y, Mehraban A, Eslamian E, Esfahani F. Disclosure of cancer information in Iran: A perspective of patients, family members, and health professionals. Iran J cancer Prev. 2011;4(3):130.
- 33. Henselmans I, Jacobs M, van Berge Henegouwen MI, de Haes HCJM, Sprangers MAG, Smets EMA. Postoperative information needs and communication barriers of esophageal cancer patients. Patient Educ Couns. 2012;88(1):138–46.
- 34. Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. 2006;12.

- 35. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. Patient Educ Couns. 2007;68(1):33–42.
- 36. Ruan J, Lambert VA. Differences in perceived communication barriers among nurses and elderly patients in China. Nurs Health Sci. 2008;10(2):110–6.
- 37. Doherty C, Doherty W. Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. J Nurs Manag. 2005;13(2):119–27.
- 38. Belcher VN, Fried TR, Agostini J V, Tinetti ME. Views of older adults on patient participation in medication-related decision making. J Gen Intern Med. 2006;21(4):298.
- 39. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Educ Couns. 2014;94(3):291–309.
- 40. Caress AL, Beaver K, Luker K, Campbell M, Woodcock A. Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. Thorax. 2005;60(3):199–205.
- 41. Anoosheh M, Zarkhah S, Faghihzadeh S, Vaismoradi M. Nurse–patient communication barriers in Iranian nursing. Int Nurs Rev. 2009;56(2):243–9.
- 42. Thompson AGH. The meaning of patient involvement and participation in health care consultations: A taxonomy. Soc Sci Med. 2007;64(6):1297–310.
- 43. Farahani MA, Sahragard R, Carroll JK, Mohammadi E. Communication barriers to patient education in cardiac inpatient care: A qualitative study of multiple perspectives. Int J Nurs Pract. 2011;17(3):322–8.
- 44. Janssen DJA, Curtis JR, Au DH, Spruit MA, Downey L, Schols JMGA, et al. Patient–clinician communication about end-of-life care for Dutch and US patients with COPD. Eur Respir J. 2011;38(2):268–76.
- 45. O'Brien MA, Ellis PM, Whelan TJ, Charles C, Gafni A, Lovrics P, et al. Physician-related facilitators and barriers to patient involvement in treatment decision making in early stage breast cancer: perspectives of physicians and patients. Heal Expect. 2013;16(4):373–84.

- 46. Nordgren S, Fridlund B. Patients' perceptions of self-determination as expressed in the context of care. J Adv Nurs. 2001;35(1):117–25.
- 47. Frosch DL, May SG, Rendle KAS, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. Health Aff. 2012;31(5):1030–8.
- 48. Caress A, Luker K, Woodcock A, Beaver K. A qualitative exploration of treatment decision-making role preference in adult asthma patients. Heal Expect. 2002;5(3):223–35.
- 49. Beaver K, Jones D, Susnerwala S, Craven O, Tomlinson M, Witham G, et al. Exploring the decision-making preferences of people with colorectal cancer. Heal Expect. 2005;8(2):103–13.
- 50. Fraenkel L, McGraw S. What are the essential elements to enable patient participation in medical decision making? J Gen Intern Med. 2007;22(5):614–9.
- 51. Shirai Y, Fujimori M, Ogawa A, Yamada Y, Nishiwaki Y, Ohtsu A, et al. Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: A randomized, controlled trial. Psycho-Oncology. 2012;21(7):706–13.
- 52. Clayton JM, Natalia C, Butow PN, Simpson JM, O'Brien AM, Devine R, Tattersall MH. Physician endorsement alone may not enhance question-asking by advanced cancer patients during consultations about palliative care. Support Care Cancer. 2012 Jul;20(7):1457-64.
- 53. Rodenbach RA, Brandes K, Fiscella K, Kravitz RL, Butow PN, Walczak A, et al. Promoting end-of-life discussions in advanced cancer: effects of patient coaching and question prompt lists. J Clin Oncol. 2017;35(8):842.
- 54. Brown RF, Butow PN, Dunn SM, Tattersall MHN, R.F. B, P.N. B, et al. Promoting patient participation and shortening cancer consultations: A randomised trial. Br J Cancer [Internet]. 2001;85(9):1273–9. Available from: http://www.embase.com/search/results?subactio n=viewrecord&from=export&id=L33081919
- 55. Brown R, Butow PN, Boyer MJ, Tattersall MH. Promoting patient participation in the cancer consultation: Evaluation of a prompt sheet and coaching in question-asking. Br J Cancer. 1999 Apr;80(1-2):242-8.
- 56. Clayton JM, Butow PN, Tattersall MHN, Devine RJ, Simpson JM, Aggarwal G, et al.

- Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. J Clin Oncol. 2007 Feb;25(6):715–23.
- 57. Eggly S, Hamel LM, Foster TS, Albrecht TL, Chapman R, Harper FWK, Thompson H, Griggs JJ, Gonzalez R, Berry-Bobovski L, Tkatch R, Simon M, Shields A, Gadgeel S, Loutfi R, Ali H, Wollner I, Penner LA. Randomized trial of a question prompt list to increase patient active participation during interactions with black patients and their oncologists. Patient Educ Couns. 2017 May;100(5):818-26.
- 58. Henselmans I, Smets EMA, de Haes J, Dijkgraaf MGW, de Vos FY, van Laarhoven HWM. A randomized controlled trial of a skills training for oncologists and a communication aid for patients to stimulate shared decision making about palliative systemic treatment (CHOICE): Study protocol. BMC Cancer. 2018;18(1):55.
- 59. Bottacini A, Goss C, Mazzi MA, Ghilardi A, Buizza C, Molino A, et al. The involvement of early stage breast cancer patients during oncology consultations in Italy: a multi-centred, randomized controlled trial of a question prompt sheet versus question listing. BMJ Open. 2017 Aug;7(8):e015079.
- 60. Brandes K, Butow PN, Tattersall MH, Clayton JM, Davidson PM, Young J, Epstein RM, Walczak A. Advanced cancer patients' and caregivers' use of a Question Prompt List. Patient Educ Couns. 2014 Oct;97(1):30-7.
- 61. Butow P, Devine R, Boyer M, Pendlebury S, Jackson M, Tattersall MH. Cancer consultation preparation package: changing patients but not physicians is not enough. J Clin Oncol. 2004 Nov 1;22(21):4401-9.
- 62. Langbecker D, Janda M, Yates P. Development and piloting of a brain tumour-specific question prompt list. Eur J Cancer Care. 2012 Jul;21(4):517-26.
- 63. Walczak A, Butow PN, Clayton JM, Tattersall MHN, Davidson PM, Young J, et al. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. BMJ Open. 2014 Jun;4(6):e005745.
- 64. Epstein RM, Duberstein PR, Fenton JJ, Fiscella K, Hoerger M, Tancredi DJ, et al. Effect

- of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: the VOICE randomized clinical trial. JAMA Oncol. 2017;3(1):92–100.
- 65. van Weert JCM, Jansen J, Spreeuwenberg PMM, van Dulmen S, Bensing JM. Effects of communication skills training and a question prompt sheet to improve communication with older cancer patients: A randomized controlled trial. Crit Rev Oncol Hematol. 2011;80(1):145–59.
- 66. Walczak A, Butow PN, Tattersall MHN, Davidson PM, Young J, Epstein RM, et al. Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers. Int J Nurs Stud. 2017;67:31–40.
- 67. Aranda S, Jefford M, Yates P, Gough K, Seymour J, Francis P, et al. Impact of a novel nurse-led prechemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs: Results from a randomised, controlled trial. Ann Oncol. 2012;23(1):222–31.
- 68. Goss C, Ghilardi A, Deledda G, Buizza C, Bottacini A, Del Piccolo L, et al. INvolvement of breast CAncer patients during oncological consultations: A multicentre randomised controlled trial--the INCA study protocol. BMJ Open. 2013 May;3(5).
- 69. Tattersall MHN, Jefford M, Martin A, Olver I, Thompson JF, Brown RF, et al. Parallel multicentre randomised trial of a clinical trial question prompt list in patients considering participation in phase 3 cancer treatment trials. BMJ Open [Internet]. 2017 Mar;7(3):e012666. Available from: http://www.embase.com/search/results?subactio
- n=viewrecord&from=export&id=L614654793 70. Buizza C, Cela H, Ferrari C, Goss C, Bottacini A, Mazzi MA, Del Piccolo L, Ghilardi
- A. Does being accompanied make a difference in communication during breast cancer consultations? Results from a multi-centered randomized controlled trial. J Psychosoc Oncol. 2021;39(2):189-203.