











**Question prompt list and shared decision-making**

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|----|---------------------------|---|------|---|---|---|
|    |                           |   |      |   | 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/hopelessness,   |   |
| 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)<br>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. |

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| 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. |







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 QPL on the promotion of SDM. In recent years, researchers have paid more attention to improving patients' participation in decision-making. They have applied a variety of interventions such as QPL to improve SDM. Researchers have already examined the effect of QPL on different variables such as total question asking (19), question-asking by content (20), the 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 I and 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.

Lack 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 undesirable to announce a "cancer" diagnosis to the patients (29,30). The majority of the physicians (75%), 249 physicians, who participated in Mobeireek et al.'s 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 end-of-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 patients in caregiving and treatment 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.

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### **Conflict of interests**

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

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