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Achieving Patient-Centered Care with Shared Decision-Making among Colorectal Cancer Patients in Israel

Olga LIPOVETSKI¹, Daniela COJOCARU²

Abstract

The Colorectal cancer (CRC) disease is one of the most common cancer disease in Israel. The course of chronic illness or disability can have a major influence on individuals' experience. The concept of patient-centeredness as an attribute of high-quality healthcare, gained national prominence and is now widely recognized as a central aspect of healthcare, paving the pathway to improve quality of life and care among cancer patients. Focus on PCC has led to the development of the shared decision-making (SDM) model, in which patients and physicians share information and values, and patients play an active role in making healthcare decisions. This study strives to generate fresh interest in furthering this important approach in Israel and sheds light on the integration of caregiver-chronic patients' perspectives regarding the decision-making processes, and the barriers and the facilitators to its implementation in chronic practice in Israel. This work is based on a two-phase mixed type research methodology, using both quantitative and qualitative means. The results of our study revealed that, in general, cancer patients desire for more involvement in their care. However, many patients are not experiencing their desired role in clinical decision-making. The possible reasons for this include structural constraints, patients and physicians' attitudes, and lack of training programs for communication skills. Our results confirm that there is a need to increase participation in the decision-making process for cancer patients. Health care organizations should strive for SDM, applying strategies for facilitating this process in chronic care.

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Keywords: patient-centered care, patient involvement in treatment plan, shared decision-making, patient-physician communication, patient empowerment, needs.

Introduction

Similar to Western world, in Israel the CRC disease prevalence ranks second in the total number of cancer cases diagnosed annually in Israel, after breast cancer in woman and prostate in men (Israel National Cancer Registry, 2019). In the cancer setting, the National Cancer Policy Forum organization defines patient-centeredness as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” [Institute of Medicine (IOM), 2011]. The PCC highlights the notion of effective patient-clinician communication and SDM as key components of PCC. These components require that informed and participatory patients interact with patient-centered professionals, who have effective communication skills and supported by a well-organized healthcare system (Karnieli-Miller *et al.*, 2017).

PCC is an ethically appealing way to promote patients’ status, empower patients and increase their autonomy. Several surveys exploring patients’ preferences for involvement in the decision-making show that patients in general want to be engaged in their care. However, patients’ preferences might vary according to demographic and other personal characteristics (Min-Chun, Ying-Chun & Wang-Chuan, 2019).

Moreover, the literature indicates that many patients perceive higher preference for shared participation, than experienced. Similarly, many physicians express support for SDM, but experience difficulties to involve patients in the treatment decision (Mathijssen *et al.*, 2020). In Israel, there is limited knowledge of how the SDM concept has been integrated into existing practice, and the limited literature revealed that SDM approach is not yet routinely implemented in Israel healthcare practice, in which medical decision have been mostly dominated by a traditional paternalistic approach, whereby the doctor makes the final decision for the patient (Bailor *et al.*, 2018).

The study addresses the state of the art of SDM as a concept receiving considerable attention in chronic healthcare in Israel, and adds to the existing knowledge as to patterns of health related behaviors with regard to the decision making process in Israel. The focus of this research is medical decision-making process and communication between chronic colorectal cancer-ill patients and Oncologists, with emphasis on SDM as an effective method for facilitating the PCC approach and patient empowerment, among cancer patients in Israel.

Models of decision-making styles in medical care context

Research on decision-making includes different types of decision-making models. Charles, Gafni & Whelan (1999) have modeled the clinical decision-making as a spectrum from a paternalistic model at one end to the informed choice model at the other end (*Figure 1*).

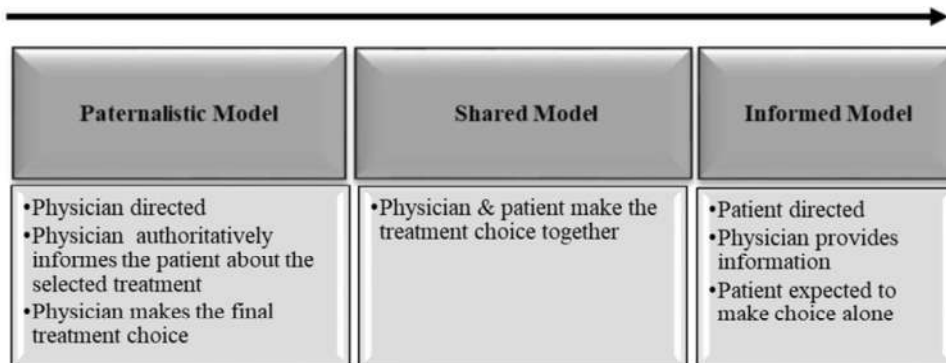


Figure 1. Spectrum of patient clinician interaction and decision-making models in health care (Charles et al., 1999)

Methodology

Research questions

This research aims to answer the following research questions: (1) What is the status of SDM in cancer clinical practice in Israel? (what is the colorectal cancer-ill patients' preferred and perceived levels of involvement in decision-making); (2) What factors are associated with colorectal cancer-ill patients preferences for involvement in decision-making; and (3) What are the facilitators, challenges and barriers to SDM implementation in the Israeli health care system?

Study design

The research methodology includes a two-phase mixed methods study, with Explanatory sequential design (Figure 2), characterized by the collection and analysis of quantitative data in the first phase, followed by the collection and analysis of the qualitative data in the second phase, which builds on, explains and widens the initial results of the quantitative component (Creswell & Poth, 2018). In the first phase, quantitative (QUAN) data are collected via web questionnaires and analyzed to inform second phase. In the second phase, qualitative (QUAL) data are collected via interviews and analyzed. Both types of data are then interpreted together.

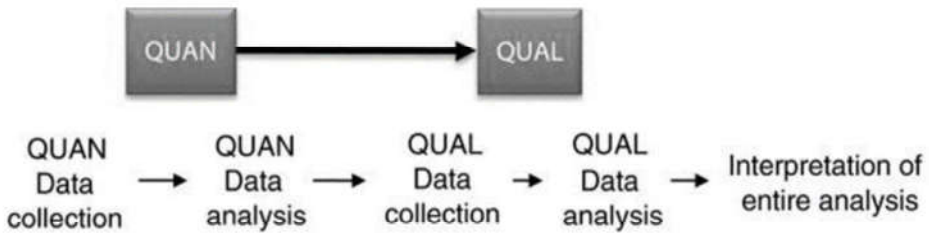


Figure 2. Two-phase sequential explanatory study design

Participants

In the first quantitative phase, study population included 145 patients, diagnosed with colorectal cancer disease for 1-5 years, treated in one of the largest Health Maintenance Organizations (HMO), named - the “Maccabi” HMO, which is a major primary care healthcare facility in the Israeli healthcare system, and 26 Oncologists, providing direct care to these patients.

For the second qualitative study, for the patients’ sample, aiming to maximize diversity, ten patients were recruited with respect to the various preferred and experiences types of decisional roles and their demographic characteristics. For the physicians’ sample, ten Oncologists recruited according to variety of demographic, occupational factors, and their usual approaches towards decision-making.

Research tools and measures

The primary technique for collecting the quantitative data was validated questionnaires, based on validated and used questionnaires in literature. *Figure 3* illustrates the research variables, measured in the questionnaires administered both patients and Oncologists in the current study.

The quantitative questionnaires for patients were submitted to the patients before and after the consultation. The physicians completed the questionnaire only pre consultations.

For the second qualitative phase, twenty semi-structured in-depth interviews were developed and used for both patients (N=10), and Oncologists (N=10). The quantitative questionnaires the patients and the physicians had completed pre and post consultation, as well as the literature review regarding the SDM concept in chronic practice, used as a framework for the interviews.

The questions in the interview guide addressing the patients focused on the issue of the thought process their preferences and support of different decision-making styles, the rational for these preferences, and as well as their perceived facilitators and barriers to shared participation in decision-making. The questions in the interview guide addressing the physicians focused on their perceived barriers and facilitators for SDM.

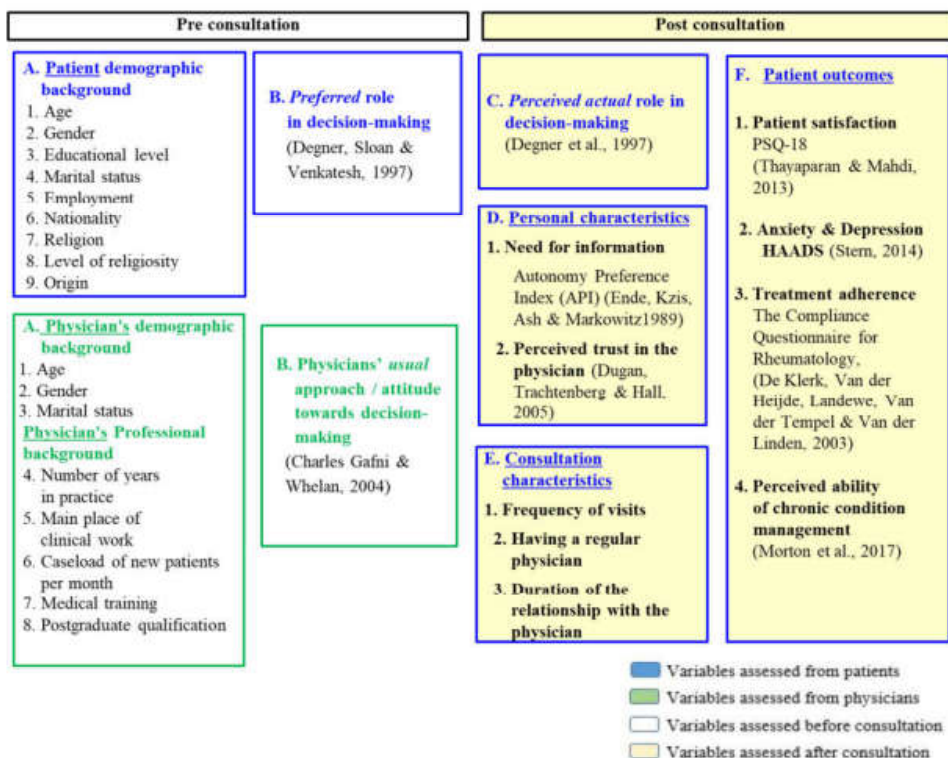


Figure 3. Research variables, measured in the of patients and physicians' questionnaires

Data collection and procedures

Phase 1: Quantitative study. After receiving the necessary approvals, invitations to participate, accompanied by a letter describing the study procedure were distributed by email used for the recruitment of the participants. Further, an informed consent form was posted by mail to participants who agreed to participate in the study. Patients expressed their consent for participation, were approached in the waiting room and complete the questionnaire before and after their medical consultation with the Oncologist. The data was processed and analyzed by SPSS, version 21, for Windows 10.

Phase 2: Qualitative study. The interviews took place face-to-face at the Oncologist's primary clinic, at the patient's home or via telephone, whichever the patient would prefer. The interviews were conducted between December 1 and December 25, 2019. The interviews with both patients and Oncologists have been conducted soon after the consultation, in which the decision about treatment

options was made. Each discussion was audiotaped and professionally thematically transcribed using NVivo Version 8.

Results

Research questions 1-2 were examined using both quantitative and qualitative means, while the fourth question was only examined using qualitative means.

Quantitative results

Participant demographics. Most of the patients were females (58.6%). The age range of patients was 38-84, with a mean age of 56 (SD = 9.34). 120 (82.8%) participants had academic education (university/college), most of them were employed (75.2%) or pensioners (18.6%). In the Oncologists' sample, most of them were males (65.4%). The age range of physicians was 47-65, with mean age 57.6 (SD = 4.70). Most of them (69.2%) had on average 18.8 years of experience in the treatment of patients diagnosed with colorectal cancer.

The status of SDM in the Israeli primary healthcare system. Figure 4 describes the comparison of patients' preferred and experienced decisional roles in decision-making process with the Oncologist.

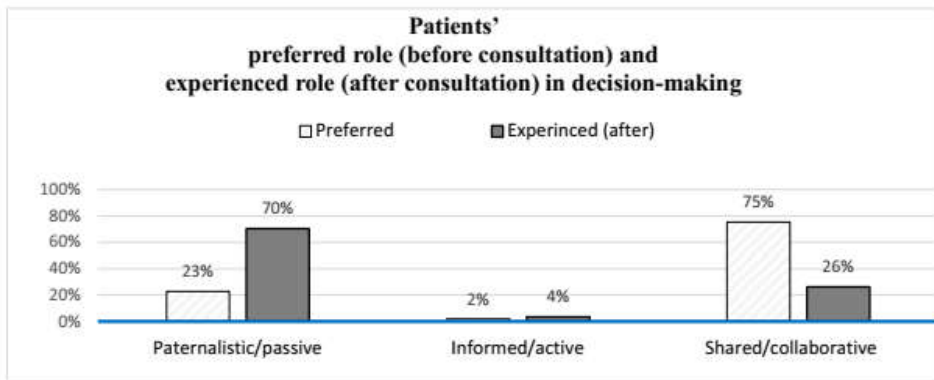


Figure 4. Patients' Preferred and Experienced role in decision-making

Most patients (75.2%, n=109) prefer shared decisional role in decision-making, while others (23%, n=33) preferred to delegate the final decisions to the Oncologist. Most patients (70.3%, n=102) perceive they were passively involved during the consultations. Figure 5 illustrates the concordance between patients' preferred and experienced decisional roles in decision-making process.

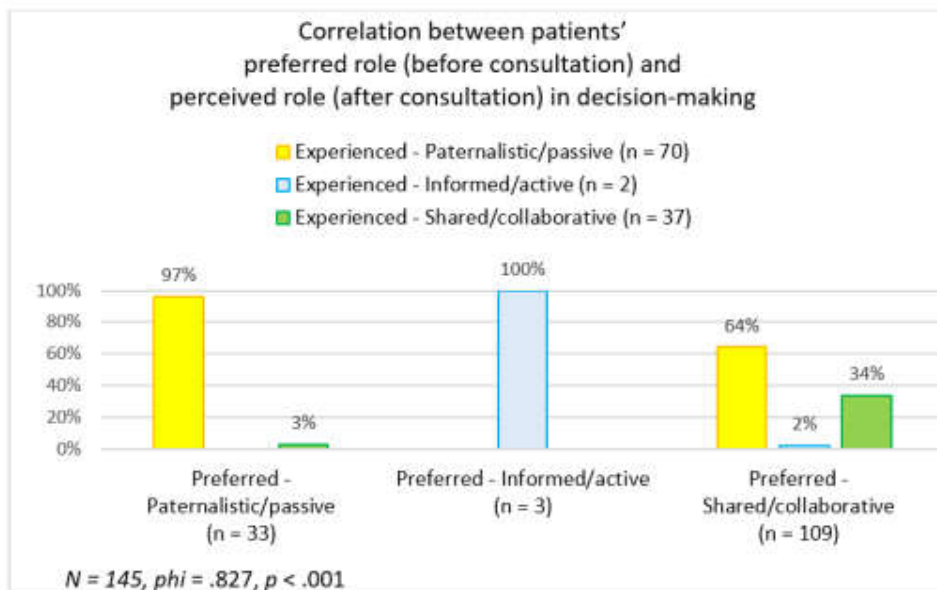


Figure 5. Concordance between Patients' Preferred role and Experienced role in decision-making

Only 34% (n = 37) of the 109 patients who preferred shared/collaborative involvement in decision making, reported that they experienced it.

Factors associated with patients' and physicians' SDM behaviors and decision-making preferences. Higher preference for collaborative decisional role was found among youngest patients (75%, mean age 53.5), patients with higher tertiary education (93%). No significant differences in patients' preference for involvement in decision-making according to gender, or marital status. In addition, cancer-ill patients' personal characteristics: need for information and their perceived trust in the physician, were significantly associated with their preference for involvement in decision-making process. The highest need for information (mean 4.54, SD = .30) and the lowest perceived trust in the physician (mean 3.70, SD = .83) were found among patients preferring the shared decisional role in decision-making. Characteristics of consultation with the Oncologist physician: frequency of visits and consultation with the same physician were significantly associated with patients' preference for involvement in decision-making.

Qualitative results

Participant demographics. Both patients and physicians' samples included five females and five males. In the patients' sample, the mean age was 61 (SD = 9.09, between 39 and 84), more than half of them (60%) had academic (university/college) education. In the physicians' sample, the mean age of the physicians was 56 (SD = 9.05, between 42 and 65), more than half of them (60%) had 16-20 years of experience in Oncology medical field.

The status of SDM in the Israeli primary healthcare system. Most patients (n=6, 60%) displayed preference for a collaborative decisional role in decision making. Only 40% (n=4) of the patients reported they experienced being involved in decision-making process.

Factors associated with patients' SDM decision-making preferences. The first most commonly reported patient-related factors, influencing patients' preference for a shared decisional role were: younger age, having sufficient knowledge, and increasing expectations of healthcare. They explained that due to their young age, patients perceived having better skills and access to web information, making them more knowledgeable, aware of their rights and the patient-centered approach, which resulted in perceived lower levels of trust in the physicians' medical judgment. Patients reported that these skills and access to information, and the awareness of the patient-centered approach, increased their expectations from the physicians and the healthcare system, and encouraged them to advocate a patient-empowering approach, which recognizes the patient as an individual with bio-psych-social aspects, respects patients for their values and needs, as a unique individual, and not as a "one of the cases". Additional commonly cited factor was consultation-related - patients' continuity of care with the same physician. Patients reported that continues familiarity with the physician greatly contributed to building a stable open-style relationship, allowing feeling comfortable expressing themselves to the physician.

Barriers and facilitators to SDM implementation in practice. Patients and physicians expressed their views regarding the inhibiting and promoting factors for patient involvement in chronic cancer care. The first perspective was of the patients. Among the ten most important barriers to SDM, three related to the patients: (1) lack of patients' assertiveness; (2) decreased self-efficacy; and (3) medical dominance (perceived inability to disagree with the physician's decision due to the perception, strived from social and cultural paradigm, of the physicians' elite status and authority). Five factors related to the professional: (1) patient was invited to SDM by the physician; (2) conduct of the professional (described as mostly technical with limited eye contact with the patient; (3) the physician does not provide adequate information; (4) the physician uses difficult language (medical jargon); and (5) negative professional's attitude towards SDM. Furthermore, two factors at the organizational level emerged: (1) limited time for consultation; and (2) high professionals' workload. Among the facilitators, perceived by patients,

the most commonly cited were: (1) accessibility to health information databases; and (2) emotional support from family or others. Three factors related to the physicians' behavior and modeling: (1) provision of choices alternative options; (2) time to consider the options at home; and (3) physicians' knowledge and familiarity with other treatment option, besides the "traditional one". One factor related to the professional and patient interaction - good rapport with the physician, based on trust and mutual respect. The second perspective was of the Oncologists physicians. Among the eight most important barriers to SDM, five barriers related to the patients: (1) patients' psychological health status; (2) patients' low health literacy; (3) overload of information; (4) patients' lack of motivation to become involved in their care; and (5) patients' perceptions of physician authority. Two factors related to the professional: (1) physicians' lack of support of patient involvement; and (2) unclear concept of SDM. Three inhibiting factors related to the healthcare system: (1) lack of tools to facilitate SDM (poor interpersonal and communication skills, and lack SDM guidelines); and (2) insufficient time. Physicians also identified factors, which in their perspective were helpful for SDM implementation in their practice. One of the facilitators related to the physicians - perceived personal incentives (including patient satisfaction scores), and one to the healthcare system - training and education (communications skills and competencies).

Discussion

The first goal of this study was to evaluate the status of SDM in the Israeli primary chronic cancer healthcare. Our combined quantitative and qualitative results revealed that a high proportion of colorectal cancer-ill patients preferred a collaborative decisional role over a passive role. This study suggests that the overall colorectal cancer-ill patients' preferred level of involvement in care tends toward a more collaborative role and is in line with the notion that patients with chronic conditions in general want to be involved in decision-making. The results of this study are in concordance with those found in the literature. Hopmans *et al* (2015) mixed methods study confirmed that cancer patients preference for decisional roles vary, with the majority preferring a collaborative approach. Nevertheless, this study also confirms previous researches' findings, suggesting that although SDM remained the preferred choice, few patients had a strong preference for the traditional paternalistic approach, preferring to leave the final treatment decision to their physician. Friedrichs, Spies, Härter & Buchholz (2016) strengthen the current research findings, found that although the majority of patients preferred sharing decisions with physicians (63%), paternalism is still widely accepted among cancer patients. An explanation to patients' preference to remain passive in decision-making was found in Cuevas, Peñate & De Rivera (2014) research, suggested that patients' preference for a more passive decisional

role could possibly be caused by their unfamiliarity of the SDM concept and the steps of the process. Some chronic patients may be inclined to select passive role preferences, when their preferences to engage in SDM, are conceptualized as preferences in making treatment decisions instead of as a process constituting of several steps. We support this explanation, as it must be taken into account that for some patients SDM might be a novel concept of decision-making. Therefore, we assume that in the current research not all components of the SDM process were equally familiar to patients, who scored their decisional role as paternalistic. This indicates that patients' choice for paternalistic decisional roles, may not always reflect their actual desire, due to inaccurate subjective understanding of SDM. Thus, we can argue that leaving the final decision to the Oncologist should not be confused with being unwilling to participate in the decision-making process.

Therefore, physicians should not underestimate patients' preferences for involvement in their care. Distinguishing the desired roles of cancer-ill patients is an essential step in promoting chronic care that respects and responds to the preferences of the individual patient.

We also found that cancer-ill patients preferred and experienced decisional roles were discordant, with a higher preference for shared participation than experienced. Previous studies, examined the extent to which chronic patients' preference for involvement in decision-making were met, revealed similar to our results, that chronic patients wanted more participation in decision-making than they actually achieved (Lin *et al.*, 2019).

It brings into question whether the patients were assessed for their preference for SDM and whether they were exposed to known interventions (i.e. physicians' skills for SDM) to enhance their level of involvement. It could be a reflection of patients' experience that they have not been assessed with their preferences for involvement in decision-making process by the Oncologists and did not feel supported by them when making the decisions. This implies predicting patients' role preferences, instead of determining it directly, might lead to miscalculations of patients' desired decisional role, and thus it should be avoided.

The second objective of this study was to evaluate the factors influencing colorectal cancer-ill patients preferences and attitudes. Our results indicated, that not only do colorectal cancer-ill patients' preferences vary, the reasons for these preferences may also be different. Our results identified that some socio-demographic factors and personal characteristics of patients could predict preferences for the shared decisional role. Younger, well-educated and patients with better access to information seem much more likely to view SDM as their preferred style of patient-physician interaction, compared to older patients. Consistent with these results, associations between age and education level of patients and preferred decisional role were also reported in previous studies (Bailoor *et al.*, 2018). This difference in view may be a result of a new generation of patients, exposed to various types of technologies and information resources,

providing them with wide scope of knowledge, decreasing their level of trust in the Oncologist's medical judgment on one hand, and increasing their confidence to engage in the decision-making process, on the other. These younger patients may have higher perceived capacities or levels of health literacy, perceiving it is much easier for them processing information about treatment options with the Oncologists.

Trust in the Oncologist emerged as another factor that we found to have an impact on patients' preference for SDM. A patient "trust in the physician" emerged as having a paradoxical role: on the one hand, it appears that in the continuity of patient-physician relationship, trust often created an inviting environment for SDM, as it facilitated communication and patients' feeling comfortable making discussions with the physician. However, mistrust in the physician made them want more involvement in decision-making, on the other. An explanation of this paradox can be found in previous studies (Kannan *et al.*, 2020), which emphasized the complexity of the concept of trust, arguing that trust can be conceptualized in various ways. These studies described patient trust as primarily arising from two domains or key areas: one of interpersonal values (respect, communication) and another of technical competence (expertise). Our results lead us to propose that patients' conceptualization of trust, might be different. Those patients, who defined trust as "the physician acting as an advocate of patients' interest and knows what is best for them", probably mainly addressed the "technical competence" conceptualization of trust and thus perceived lower level of trust, those patients were mostly young and well-educated with preliminary knowledge, questioning the Oncologists' competence, expertise and knowledge what's best for them. In contrary, patients treated by the same physician developed trustful relationship with the physician and in this case conceptualized trust on interpersonal level, and thus felt comfortable to be engaged in decision-making.

It was also identified in the current research that patients' perceptions regarding quality of care have made a shift from the physician-oriented approach to a more patient-centered approach, which reflected in their increased expectations from healthcare and professionals. Patients highlighted the importance to be recognized as unique, respected and acknowledged for their values and needs, and expected these qualities to be reflected within the encounters with their Oncologists. According to Aminaie Mirlashari, Lehto, Lashkari & Negarandeh (2019) the traditional paternalistic doctor- patient relationship usually emanate from social-cultural paradigm. However, in the last two decades cultural views have changed, usually in developed and modern societies, and the pendulum swung to a more patient-centered model, and the idea of medical autonomy was replaced by the shared model according to which the patient has become a key player. This new vision of the patient role and attitudes towards the management of their care is advocated in several studies (Berger *et al.*, 2017), which found that the contemporary patient in the patient-centered climate in chronic healthcare, may demand high quality services.

The third objective of the current research was to assess the barriers and the facilitators to SDM implementation in chronic cancer primary healthcare in Israel, from both patients and physicians' perspective. Among the barriers found in this study, the most common were related to the patient-physician interaction and organizational barriers. Physicians' technical conduct, usage of difficult language and unrecognition of the patients' role, reflected in their dismissiveness and inattentiveness regarding the patients' opinions were largely perceived as barriers by patients.

This finding correspond well with previous studies (Berman & Chutka, 2016), which suggested that the SDM process for a patient requires a holistic approach with considerations that go beyond the diagnosis of a disease. It requires many skills along with professional knowledge. Patient understanding, empathy, honesty, being transparent, good listener and patient-centered are important components. These results widen our understanding that for developing this kind of relationship not only continuity of care and might promote patients' trust in the physician for developing good relationship with the physician, but also the communication skills of both patient and physician.

In addition, physicians reported that lack of tools such as educational training programs for interpersonal and communication skills, and lack of guidelines and protocols for SDM application, as barriers for their application of this approach. This matter was also confirmed by previous studies (Williams, Cragg, Van den Broek & Chavannes, 2018) claiming that SDM is not an inborn talent but consists of specific behaviors that can be taught. Other previous studies (Covvey *et al.*, 2019) also found that teaching physicians about SDM could lead to improved staff communication skills, decision-making coaching, and an increase in patients' engagement in decision-making. Hence, it is strongly advised to practically strengthen physicians' communication skills, knowledge of the SDM principles and they way to apply this approach. Identifying influential people (i.e. medical healthcare personal and instructors as role models) was another solution to physicians' lack of training and knowledge regarding the SDM principles and guidelines for its application, underscored in this and other studies (Voogdt-Pruis *et al.*, 2019).

Finally, high professional workload perceived by the patient as another barrier to SDM. High workload and pressure, under which the Oncologists work, greatly limited their participation in terms of sufficient time, fostering physicians' emotional distress and inability to encourage patients' participation. The effect of physicians' workload on their decision-making behavior was examined in various studies (Shurtz, Eizenberg, Alkalay & Lahad, 2019), which were consistent with the findings of this study, found that the time-pressed everyday clinical practice was identified as a barrier to SDM. In the Israeli healthcare HMO each medical consultation rates above 3 to 4 per hour may lead to suboptimal visit content and lack of opportunity for SDM. To make the most visit time available, we recommend

that medical training contain improved instruction in patient-doctor relationships and time management.

With regard to the facilitators, patients' access to medical information, patients' support and physicians' personal incentives recognized as the most common. Oncologists discussed their personal incentives, such as patients' satisfaction ratings as a motivating factor for them to involve patients in their care. They were motivated by these incentives to give patients "more than expected". Previous literature (Mathijssen *et al.*, 2020) also confirmed the idea that patients' satisfaction with care is a guiding principle of professional practice and is one of the professional if not personal rewards of being a healthcare provider.

Conclusion

Our study demonstrated the complexity of factors influencing cancer patients' preferences for participatory roles in decision-making. It is clear that there is a need to increase participation in the decision-making process for cancer patients, in Israel. By understanding the typology of patient preferences for participatory roles in decision-making and the predictors of patients' involvement in decision-making, we can make it easier for clinicians to pursue patients' preferred level for involvement and promote SDM application in practice. The findings of the current research have potential implications for quality improvement efforts, requiring multifaceted approaches ranging from education and training programs for both patients and physicians regarding the concept of SDM and the guidelines for its implementation, to supportive tools strengthening communication skills.

Tailored implementation strategies targeting factors related to all levels of the healthcare system are needed to make SDM in cancer care a practical reality. This research confirmed that the notion of patients' participation in decision-making is a method of improving the quality of care provided to cancer patients. Our findings support the notion that SDM involves much more than the moment a decision is made, and illustrate that a strong and trustful patient-provider relationship and effective communication throughout the visit facilitate SDM and help overcome communication barriers.

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