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**Patient Centered Care in Chronic Conditions: The SHARE Approach in Israel**

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A handwritten signature in black ink, appearing to be 'D. Cojocaru', is located in the lower-left quadrant of the page. The signature is fluid and cursive, with a large loop at the end.

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# 1. Introduction

The present study is focused on the SHARE approach, which aims to achieve patient-centered care (PCC) with shared decision-making (SDM) among Israeli patients with chronic conditions. Effective patient-physician communication and SDM are key components of PCC. The patient-physician relationship is the core of the healthcare system in many respects, and interaction between physicians and patients remains a central focus in the study of health in a variety of health disciplines. Focus on patient-physician interaction, collaboration, PCC and decision-making (DM) has led to the development of the SDM model. According to this model, patients and physicians exchange information, share values and beliefs, and patients are activated in the decision-making process (DMP) (Kadmon et al., 2016). This is the gold standard in medical care an ethically compelling method of fostering the PCC (Chirk-Jenn et al., 2013).

Several studies, exploring the preferences of patients for participation in the DMP, have shown that patients generally want to be involved in the DMP regarding their care. The SDM definition has, however, been perceived and interpreted differently in various social and cultural contexts. Therefore, implementation of SDM appears to be difficult, even in countries where government formally endorses SDM, such as Israel. In Israel, there is little information regarding how the SDM principle is incorporated into practice. On the micro level, little is known about the desires of patients to be involved in the DMP. At a macro level, it is unclear if the SDM model can be adjusted to Israeli healthcare system, and its relevance to Israeli healthcare culture in chronic conditions management (Miron-Shatz et al., 2012).

The present study addresses the current state-of-the-art SDM as a concept receiving considerable attention in chronic healthcare conditions in Israel. Moreover, it aims to add to existing knowledge of patterns of health-related behaviors regarding DMP within this practice in Israel. The present study strives to evoke fresh interest in furthering the SDM approach in primary chronic care in Israel, shedding light on the integration of caregiver-chronic patients' perspectives regarding DMP, the inhibitors and facilitators of its implementation in primary chronic practice, as well as its resulting benefits for patients, their families and the healthcare system.

## **1.1 General Theoretical Perspective**

### **The Chronic Care Model (CCM)**

In the light of the complexities of chronic diseases, chronic care programs need more than evidence about appropriate diagnostic procedures and therapies. The CCM is, therefore, structured as a well-established organizational structure for improving and management of chronic disease treatment (Bodenheimer et al., 2006). The CCM seeks to achieve improved outcomes in chronic healthcare, through more efficient communication between educated patients and trained and supportive medical professionals. This primary care model is based on the premise that changes in care incorporates patients, healthcare providers and healthcare system at the program level. The CCM consists of six distinct concepts, defined as modifiable elements for improving care in healthcare systems on the community, organization, practice and patient levels (Davy et al., 2015): (1) organizational support; (2) clinical information systems; (3) delivery system design; (4) decision support; (5) self-management support; and (6) community resources.

### **The Model of Patient-Centered Care (PCC)**

PCC is now widely accepted as a core aspect of healthcare. Effective patient-physician communication and SDM are widely acknowledged as key components of PCC. These components ensure that informed, motivated and activated patients and their family members interact with patient-centered healthcare professionals with good communication skills and be encouraged by an open and well-organized healthcare system. Based on previous evidence, patient engagement can be a powerful instrument for achieving better PCC and quality of care (Epstein & Street, 2011). The provision of PCC has the ability to enhance engagement, communication and health outcomes as for patients and the healthcare system. The CCM and PCC models have become an important theoretical paradigm for quality improvement in chronic care. In the present study, these models served as a theoretical framework, because they emphasize important steps towards improved quality of chronic healthcare, which can be achieved by improving patient-physician communication and patients' involvement in treatment decisions.

### **Shared Decision-Making (SDM)**

The scientific evidence on DM (Charles et al., 1997; 1999) encompasses different types of DM styles, which vary depending on the roles that health professionals and patients play in the final treatment choice. The DM spectrum ranges from the paternalism model, through the SDM model,

and up to the informed decision-making (IDM) model. In the paternalistic model, the physician makes the final treatment decision, without considering patient needs and values. In IDM model, the patient has the absolute control over the treatment DMP, after receiving all the information. *The SDM model*, involves both the patient and the practitioner, sharing information on both sides, taking steps to establish consensus on agreeing on the treatment to be taken, within the evidence-based medical knowledge and patients' preferences and values are met and integrated into a single process. SDM represents a meaningful approach to the improved quality of care by promoting PCC.

## 1.2 Conceptual framework

Figure 1 describes the conceptual framework of the present study and patterns of interaction between research variables, and main concepts.

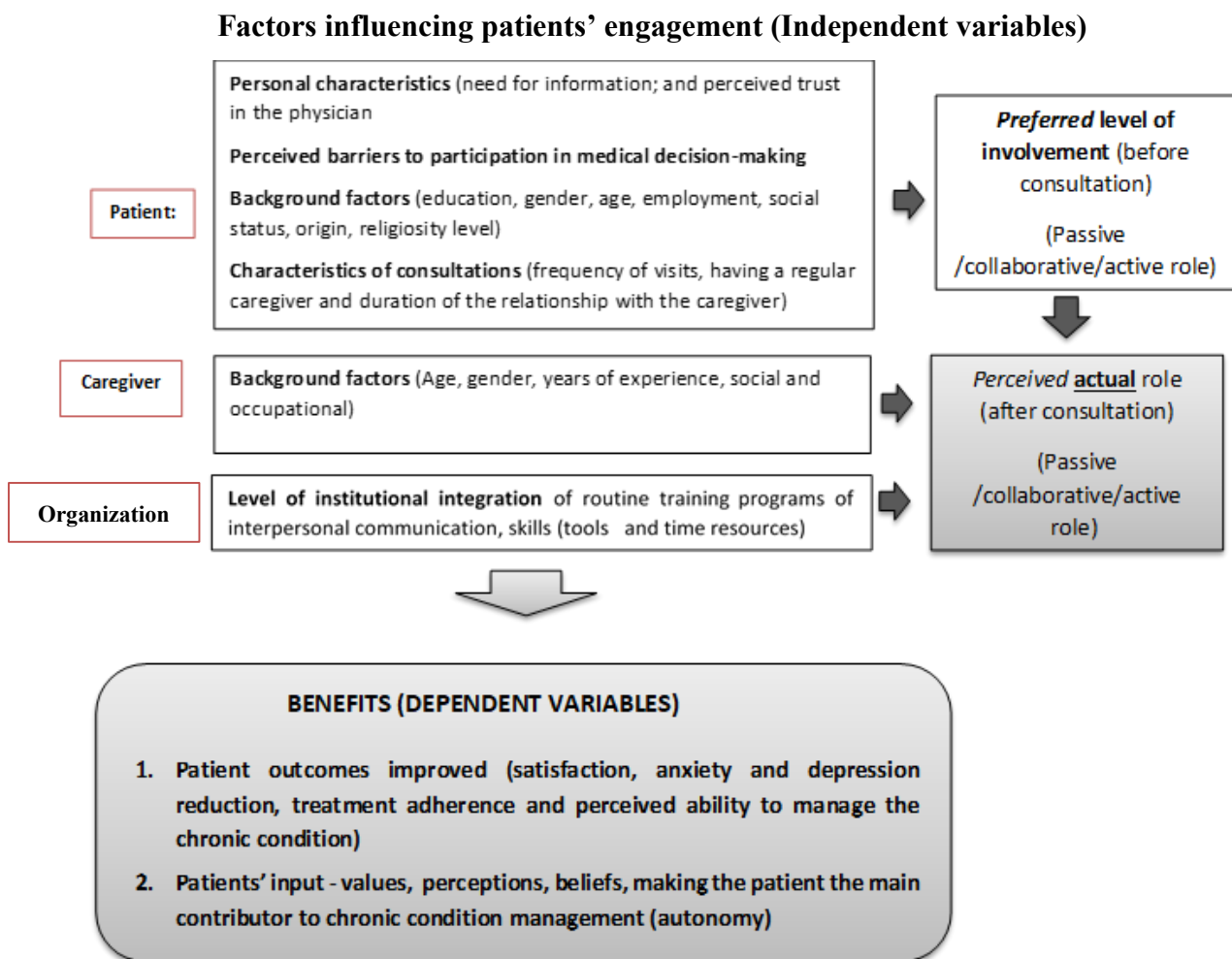


Figure 1. SDM implementation in Israeli healthcare culture conceptual framework as constructed to the present study

Evidence-based medicine proves that SDM can improve outcomes in chronic diseases. Yet, the use of SDM is not as implemented in Israel to its maximum potential. There are many possible reasons for this, including patient-related, caregivers-related factors and healthcare (organizational) structural constraints (Miron-Shatz et al., 2012). All parties concerned, i.e., national (healthcare policy makers), medical professionals, and patients themselves, need to participate in the success of SDM implementation (Barry & Edgman-Levitan, 2012). Additionally, all parties concerned can benefit from SDM, which ultimately improves healthcare and patient outcomes.

## 2. Research approach and methodology

### 2.1 Research design

A mixed-method methodology was adopted, using both quantitative (questionnaires) and qualitative (interviews), applying the Sequential Explanatory Design approach (Figure 2), as the research design, as the best suitable for the present study (Creswell & Poth, 2018). The complexity of the present study issues calls for more than numerical answers in a quantitative context or words in a qualitative sense. Therefore, a combination of both types of approaches to data collection provides the most comprehensive problem analysis (Tashakkori & Teddlie, 2003). The Sequential Explanatory Design in the present study consists of two distinct phases. The first is quantitative data collection, followed by the second qualitative data collection, based on quantitative results. The rationale underlying this approach is that is the best way to get in-depth comprehension, interpretation and verification of the quantitative data and the research problems, examining participants' perspectives on the factors involved in patient engagement in decision-making processes (DMPs) in chronic health care.

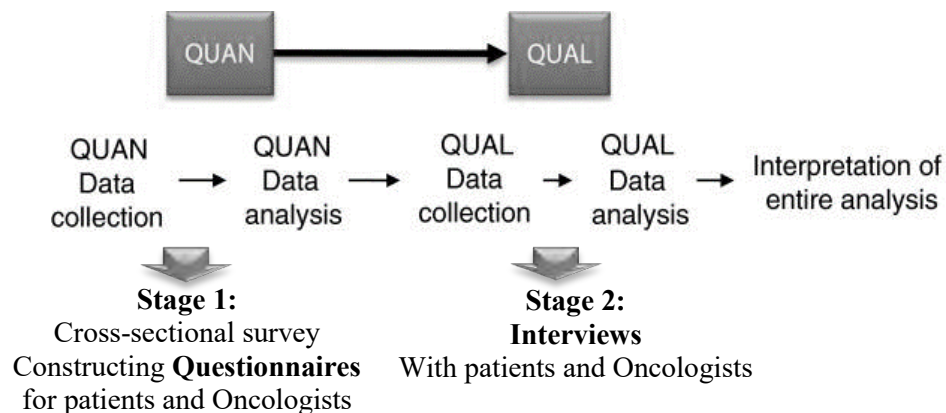


Figure 2. Sequential explanatory mixed methods design (Creswell & Poth, 2018)

A summary of the research questions and research hypotheses (according to the specific research aims) is presented in Table 1.

The ultimate aim of the present study is to explore factors involved in patient engagement in decisions made regarding management of chronic conditions, focusing on cancer-diagnosed patients. The specific aims of the study are presented in Table 1.

Table 1: *Summary of research aims, questions and hypotheses*

Aims	Questions	Hypotheses
<p>(1) <i>To investigate the status of shared decision-making (SDM) in chronic (cancer) clinical practice in Israel</i></p>	<p>1. <i>What is the status of SDM in chronic (cancer) clinical practice in Israel?</i></p> <p>a. <i>What are chronic (cancer) patients' preferred (pre-consultation) levels of involvement in DMPs in Israel (their decisional role preferences)?</i></p> <p>b. <i>What are chronic (cancer) patients' perceived (post-consultation) levels of involvement in DMPs in Israel (their perceived decisional roles)?</i></p> <p>c. <i>What are physicians' approaches to DMPs, applied in clinical practice with cancer patients?</i></p>	<p>(1.1) <i>Most cancer patients, attending primary care facilities, prefer a shared/collaborative decisional role (SDM) in DMPs with their physician pre-consultation</i></p> <p>(1.2) <i>Most cancer patients, attending primary care facilities, perceive they were passively involved after consultations with their physician</i></p> <p>(1.3) <i>Cancer patients' preference for involvement in decision-making (DM) (pre-consultation) and their perceived decisional role in DM (post-consultation), would be discordant, with a higher preference for shared participation than experienced</i></p> <p>(1.4) <i>Physicians mostly adhere to a paternalistic approach to patients' engagement in DM</i></p>



<b>Aims</b>	<b>Questions</b>	<b>Hypotheses</b>
<p>(2) <i>To examine factors associated with patients and physicians' decision-making preferences and behaviors, during routine care of cancer-ill patients</i></p> <ul style="list-style-type: none"> <li>• To explore the relationship between chronic (cancer) patients' decisional preferences and demographic, personal and consultation factors</li> <li>• To explore the relationship between physicians' usual approach to DM, applied in chronic practice and demographic variables</li> </ul>	<p>2. <i>What factors are associated with patients and physicians' SDM behaviors and DM preferences, during routine primary care of cancer-diagnosed patients?</i></p> <p>a. What factors are associated with cancer patients' <i>preferred</i> level of involvement in DM pre-consultation, in Israel?</p> <p>b. What factors are associated with physicians' usual approach to DM applied in cancer patient practice, in Israel?</p>	<p>(2.1) Cancer patients' <i>socio-demographic</i> factors, <i>personal characteristics</i> (need for information, perceived trust in the physician) and <i>characteristics of consultation</i> (frequency of visits, having a regular caregiver and duration of relationship with the caregiver) would be associated with their <i>preference</i> for involvement in DMPs with their physician pre-consultation</p> <p>(2.2) There are differences in physicians' usual approach to DM according to socio-demographic factors (gender, age, and occupation)</p>
<p>(3) <i>To assess the effect of SDM on chronic patients' health outcomes (satisfaction from care, anxiety and depression, treatment adherence and perceived ability of chronic condition management)</i></p>	<p>3. <i>How does cancer-ill patients' involvement in DM relate to their health outcomes?</i></p>	<p>(3.1) Cancer-ill patients, perceiving their participation in DM post-consultation as shared, report of higher levels of satisfaction, treatment adherence and improved perceived ability of management of their cancer disease and lower levels of anxiety and depression</p>

Aims	Questions	Hypothesis
<p>(4) <i>To investigate facilitators, challenges and barriers to SDM implementation in the Israeli primary healthcare system affecting clinical practice of chronic conditions</i></p> <ul style="list-style-type: none"> <li>• To identify key facilitators and barriers to SDM implementation from the cancer patients' and the caregivers' perspectives</li> </ul>	<p>4. <i>What are the facilitators, challenges and barriers to SDM implementation in the Israeli primary healthcare system affecting the clinical practice of chronic conditions?</i></p> <p>a. What are the factors that hinder or promote cancer <i>patients'</i> ability to participate in DM during clinical consultations, in Israel? (Which facilitators and barriers patients perceive as important for the application of SDM in cancer patient practice, in Israel?)</p> <p>b. What are the facilitators and challenges (barriers) for <i>caregivers</i>, effecting their ability to engage SDM in clinical practice of cancer, in Israel? (Which facilitators and barriers physicians perceive as important for the application of SDM in cancer patients' practice, in Israel?)</p>	
<p>(5) To discuss the relevance of SDM to Israeli healthcare culture in management of chronic conditions, focusing on cancer patients</p>		

## Phase I - The Quantitative Phase

### Research Instruments and Measures

The first, quantitative phase of the present study focused on research questions 1-3, identifying the status of SDM in the Israeli cancer chronic healthcare, the factors affecting on patients and physicians' DM preferences, as well as the impact of SDM utilization among chronic patients on patients' outcomes. The primary quantitative data collection technique was validated questionnaires. The final validated versions of the questionnaires for both patients, comprising 69 items, and physicians - 9 items, taken from validated questionnaires in the empirical literature. At the end of the validation procedure, three questionnaires were prepared (Figure 3): (1) Patient – pre-consultation; (2) Patient – post-consultation; and (3) Physician – pre-consultation. The questionnaires were submitted to the patients *before* and *after* the consultation, and to physicians only pre-consultations. An explicit approval and permission for using the standardized instruments for the current research purposes was obtained from the authors. Figure 3 illustrates the research variables, measured in the questionnaires administered to both patients and oncologists.

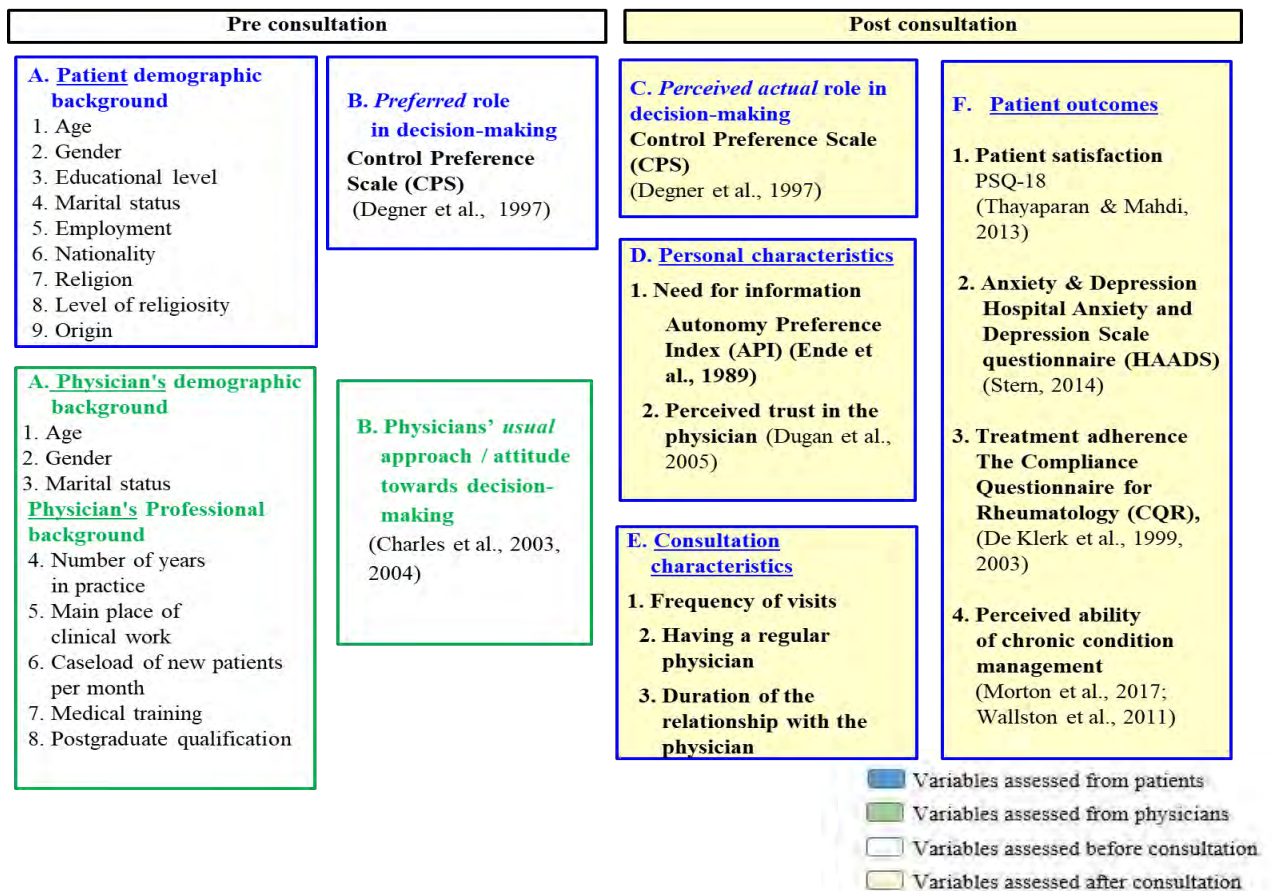


Figure 3. Research variables, measured in patients and physicians' questionnaires

## **Research population and sample**

The research population comprised 145 patients, treated for colorectal cancer disease (CRC) 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. These patients complied with the following eligibility criteria:

1. Adults (age above 18).
2. Treated for CRC disease, for one to five years (patients with other chronic diseases were excluded).
3. Speak Hebrew and/or Russian.

The research population also included 26 oncologists, who provided direct care to CRC diagnosed patients, in a large Israeli HMO, named - the “Maccabi” HMO, met the eligibility criteria:

1. Adults (age above 25).
2. Oncologists providing direct care to patients receiving treatment for CRC type of cancer.
3. Speak Hebrew and/or Russian

The questionnaires were administered to 150 patients, and 145 were completed (response rate - 97%), responded to the questionnaire before and after the consultation with their oncologist. Above half of the patients' sample were women. Their mean age was 56. Most of the patients were employees or pensioners. The questionnaires were also administered to 30 oncologists, and 26 were completed (response rate - 87%). Most of them were men. Their mean age was 57.6. Most of their medical training was in Israel, or Israel combined with the former USSR. All of the oncologists worked in “Maccabi” HMO. Most of them (69.2%) had 6- 10 new cases of CRC-ill patients per month and had 18.8 years of experience on average in the treatment of patients diagnosed with CRC.

## **Quantitative data collection and procedures**

After obtaining the necessary approvals, invitations to participate, accompanied by a letter describing the research procedure were distributed by email following a phone call from the researcher of the present study, the purpose of which was to recruit the participants and obtain the approval for their participation. Participants were asked to respond by mail to the invitation, thereby expressing their consent to participate in this study. Once the invited participant opted to participate, the researcher of the present study then followed up with direct contact (via telephone) with each of the participants, in order to receive the consent of the prospective

research participants, provide an overview of the research process and coordinate the schedule and the location for responding to the questionnaires. Then, an informed consent form was posted by mail to the participants who had agreed to participate in the present study.

Oncologists who agreed to participate in the present study responded to the questionnaire before consultations. Patients, who met the present study eligibility criteria and expressed their consent for participation, were approached in the waiting room and responded to the questionnaire pre and post their medical consultation with the oncologist.

### **Quantitative Data analysis**

The data were processed and analyzed by SPSS, version 21, for Windows 10. A significance level of 0.05 was adopted for all hypothesis tests. Demographics, characteristics of the sample and research data were analyzed descriptively using means, standard deviations for continuous variables and frequency, percentage and range distributions for categorical variables.

The hypotheses were tested using  $\chi^2$  for discrete variables (nominal or ordinal), and one-way analysis of variance and (ANOVA) for continuous variables. In the ANOVA (Analysis of variance) - the source of variance and its significance level were tested using Scheffe's test ( $p < .05$  at least), because the number of patients which reported each SDM style was less than one hundred and the number of participants in each decision-making style was different.

### **Phase II - Qualitative phase**

The second, qualitative phase of this study focused on explanation, clarification and validation of the statistical results obtained in the first quantitative phase. A qualitative process was the appropriate research strategy for answering the research questions (2 and 4) in an explorative way, leading to alternative explanations and new insights, and deeper understanding regarding patients and physicians' perceptions.

The aims of the qualitative phase of the present study were:

- 1) To obtain in-depth knowledge of the factors associated with chronic patients' decisional role preferences in the DMP. More specifically, understanding the rationale underpinning their preference for different levels of involvement in DMP regarding the cancer disease treatment
- 2) To explore patients and physicians' perceptions of SDM
- 3) To assess the facilitators and inhibitors to SDM implementation in chronic (cancer disease) practice, from patients and physicians' perspective

### **Research instruments and measures**

Twenty semi-structured in-depth interviews were developed and conducted with both patients (N=10), diagnosed with CRC disease, and oncologists (N=10), providing direct care to these patients. The interview was conducted according to a topic guide, determined by the researcher of the present study according to the quantitative results, the research questions and the systematic literature review, regarding the SDM in chronic practice, which served as the framework for the interviews.

The interview guides developed for the patients included 31 open-ended questions, and for the physicians, 23 open-ended questions. The questions addressing the patients focused on the thinking process of their general opinions regarding the concepts of SDM, their perception of this process, patients' preferences for different levels of involvement in DM, as well as their perceived facilitators and inhibitors to shared participation in DM. The questions addressing the physicians focused on the thinking process of their general opinions regarding the concepts of SDM with the patients regarding treatment options, as well as the advantages and disadvantages of applying this approach in practice. Furthermore, their usual approach to SDM implementation in practice, as well as their perceptions and perspectives regarding facilitators and inhibitors to SDM implementation in chronic disease practice.

Both patients and physicians' interview guides were validated for face, construct and content validity methods. The English version of the interview guides for both the patients and the oncologists were translated into Hebrew and Russian by through a process of forward backward translation.

### **Data collection and procedures**

After completing the quantitative results analysis, the researcher of the present study contacted the eligible participants by mail or telephone, according to the needed clarification of the response, in order to invite them to participate in a short interview and coordinate date and location for it. Participants received the interview questions prior to the scheduled interview and were informed about the research and the interview aims.

The interviews were conducted from December 1 through December 25, 2019. The interviews with the patients took place face-to-face at the oncologist's primary clinic, at the patient's home or via telephone (following the same protocol as the face-to-face semi-structured interviews), whichever the patient preferred, and lasted 30-45 minutes on average. With the oncologists, the interviews took place face-to - face interviews in person at the physician's office, or over the phone, lasting an average of 20 minutes. The researcher of the

present study aimed to conduct interviews until saturation had been reached, that is, no new arguments or topics were brought up, with a minimum of ten interviews with patients and ten with oncologists responding to quantitative questionnaires.

The interviews with both patients and oncologists were conducted soon (approximately two-three weeks) after the consultation, in which the decision about treatment options was made. The patients and the oncologists did not have to be interviewed directly after every consultation, due to the nature of the Sequential Explanatory Design approach adopted in the present study. According to this approach, the first quantitative phase served as a framework for the recruitment of the eligible participants for the interviews, chosen based on the variation of the patients and oncologists' different responses to the variables examined by the quantitative questionnaires.

Aware that the researcher's related factors could also affect the process of conducting semi-structured interviews, all interviews were conducted by a qualified psychologist, who was an experienced interviewer trained to ensure consistency across interviews and maintain patient's safety. Following each interview, the psychologist discussed it with the researcher.

All participants were provided with information sheets along with their consent forms, and were asked to give their permission to record the interviews.

### **Thematic analysis of the interviews**

Two research assistants independently performed thematic data analysis using NVivo Version 8, qualitative data analysis software - QSR international software for qualitative data analysis, in order to collect, organize and analyze the data (a trained psychologist, an expert in qualitative research methods and the researcher). When analyzing the data, the research assistants were guided by the visual model of qualitative analysis (Creswell & Poth, 2018).

Recordings of the semi-structured interviews were transcribed verbatim with patients and physicians. After the interviews were recoded and transcribed, the interviews were recorded and analyzed (Creswell & Poth, 2018). This enabled interpretation of the text. Coding was performed both deductively and inductively. The process was guided by a predefined coding framework based on topics from the questionnaires and on concepts that the empirical literature associated with SDM implementation and, thus, new codes were derived from the interview data.

In the final phase, the researcher of the present study together with the research assistants reviewed and validated the results, summarized the meaning of the quantitative and qualitative data and discussed to what extent and in what ways the qualitative results helped in explaining

the quantitative results and indicated new insights and lessons learned.

### **Research Population and sample**

A stratified purposeful sample was obtained for the purpose of the second, qualitative phase of the present study in order to understand the central phenomenon based on quantitative results. The research also chose participants who were best suitable for a qualitative study, namely participants in this qualitative sample were a subset of the participants in the first quantitative sample. Participants were recruited based on maximum variation sampling, according to topics and variables identified by the researcher as necessary for further explanation and exploration, in which a researcher samples cases or individuals differing in some characteristic and in their answers to the questionnaires.

For the patients' sample, the researcher of the present study chose five females and five males from different age groups, educational levels and employment status and with different preferred and experienced levels of involvement in DMP. For the physicians' sample, five females and five males were chosen from different age groups, professional experience levels, caseload, medical training and usual approaches towards DM applied in practice with CRC-ill patients.

### **3. Research approval and ethical considerations**

The Request for Review Form for ethical approval of this study was submitted to the Faculty of Socio-Political Sciences ethics committee, the Sociology and Social Work Department ethics committee and the Maccabi HMO Helsinki ethics committees for non-interventions studies.

For all the participants in this study an informed consent form was created (patients and physicians). The form confirmed that the participants had certain rights assured and protected, and agreed to participate in the present study. Participants' anonymity was maintained by coding each returned questionnaire numerically and keeping the answers confidential. In addition, anonymity was ensured, and participants were guaranteed confidential handling of the data collected.

### **4. Results**

This chapter presents the findings from the quantitative part, obtained by analyzing questionnaires completed by patients and oncologists. The next chapter (the Discussion and Interpretation chapter) presents the findings from the qualitative stage and also the discussion and interpretation of the way the quantitative findings were validated and explained by the



qualitative.

The first and the third research questions were examined using only the quantitative instruments. The second research question was examined using both quantitative and qualitative instruments, while the fourth question examined only by using qualitative instruments.

#### **4.1 Phase 1: Quantitative findings (obtained from research questions 1 - 3)**

##### **Findings Obtained from Research Question 1 - hypothesis examination:**

*What is the status of shared decision-making (SDM) in chronic cancer disease clinical practice in Israel?*

75% of the patients reported before consultation with their physician that they *preferred* shared/collaborative role in decision-making process (DMP) compared to 23%, who reported that they *preferred* a paternalistic/passive role. 70% of the patients *perceived* after consultation with their physician that they were passively involved in DMP (paternalistic/passive approach), compared to 26%, who *perceived* their role as shared/collaborative. Hypothesis (1.1) and (1.2) were corroborated. In addition, cancer-ill patients' *preference* for involvement in DMP (pre-consultation) and their *perceived* decisional role (post-consultation), was *discordant* ( $\chi^2_{(1)} = .827, p < .001$ ), with a higher preference for shared participation than experienced. Only 34% of patients, who preferred collaborative involvement in DMP, reported after consultation that they had experienced it. Hypothesis (1.3) was corroborated. Oncologists mostly adhere to the paternalistic approach (69%). Only 19% of them reported that they used the shared/collaborative approach. Hypothesis (1.4) was corroborated.

##### **Findings Obtained from Research Question 2 - hypothesis examination:**

*What factors are associated with patients' and physicians' SDM behaviors and DM preferences, during routine in primary care of cancer-diagnosed patients?*

The difference in patients' *preferred* level of participation in DM was examined according to patients' *socio-demographic* factors, *personal characteristics*, and *consultation characteristics*. With regard to patients' *socio-demographic factors*, the differences in patients' preferences were significant according to their age ( $F_{(2,14)} = 21.68, p < .000$ ), education level (*Cramer's v* = .355,  $p < .000$ ), employment (*Cramer's v* = .334,  $p < .000$ ) and origin (*Cramer's v* = .384,  $p < .001$ ). Most of the patients, who preferred the shared participation, were significantly younger, with higher education level (tertiary education), employed, and originally from Israel or USSR-Russia, as compared patients who preferred paternalistic/passive

involvement in DM. Non-significant differences ( $p > .05$ ) in preferred DM role were found between men and women, and according to patients' marital status, and between different religiosity levels of patients.

With regard to patients' *personal characteristics*, the differences in patients' preferences were significant according to their need for information ( $F_{(2,14)} = 21.68, p < .003$ ), and their perceived trust in the physician ( $F_{(2,144)} = 9.09, p < .003$ ), with the highest need for information and the lowest perceived trust in the physician reported by patients preferring the shared/collaborative involvement in DM, compared to those who preferred the paternalistic/passive decisional role.

With regard to the *consultation characteristics*, the differences in patients' preferences were significant according to having a regular physician (consultations with the same physician) (*Cramer's  $v = .349, p < .000$* ), and frequencies of visits (*Cramer's  $v = .376, p < .000$* ). Most patients reported preferring the shared/collaborative, reported they were treated often or always by the same physician (had continuity of care) and visited their oncologist over five times a year, significantly more than those who reported preferring the Paternalistic/passive decisional role. The differences in the duration of the relationship with the oncologist between patients' preferred decisional role in DM were not significant ( $p > .05$ ).

These findings corroborated hypothesis (2.1) regarding patients' demographic data: *Age, education level, employment, and origin*, but were refuted regarding *gender, marital status, and religiosity level*. Hypothesis (2.2) was refuted. Small but insignificant differences ( $p > .05$ ) were found in *oncologists' usual approach to DM* according to their *socio-demographic factors*.

### **Findings Obtained from Research Question 3 - hypothesis examination:**

*How does cancer-ill patients' involvement in DM relate to their health outcomes?*

Significant differences were found in *overall patient satisfaction* ( $F_{(2,142)} = 164.32, p < .000$ ), *treatment adherence* ( $F_{(2,142)} = 55.69, p < .000$ ), *perceived ability of chronic condition management* ( $F_{(2,142)} = 54.68, p < .000$ ), and *depression* (*Cramer's  $V = .49, p < .001$* ) and *anxiety levels* (*Cramer's  $V = .41, p < .001$* ), according to patients' experienced participation. Patients perceiving their *experienced participation* in DM post-consultation as shared/collaborative, reported higher levels of satisfaction, treatment adherence and perceived ability of managing their cancer disease and lower levels of anxiety and depression compared to patients, who perceived their experience in DM as paternalistic/passive. Hypothesis (3.1) was corroborated.

## **4.2 Phase 2: Qualitative findings (research questions 2 and 4)**

The content analysis of 20 semi-structured interviews gave rise to 8 themes and 15 categories. Table 2 presents the themes and categories derived from the content analysis.

Table 2: *Themes and categories obtained from the content analysis of research questions 2 and 4*

No.	Theme	Categories
1	Factors associated with patients' DM preferences	Patients perception of sufficient knowledge and information
		Social/cultural perception of physicians' authority
		Trust in the physician
		Continuity of care with a usual physician
		Increasing expectations of healthcare
2	Patient-related inhibitors to SDM	Making decisions because of despair
		Exposure to information sources
3	Patient-related facilitators to SDM	Patients' emotional support from family and others
4	Physician-related facilitators to SDM	Perceived personal incentives
Ambivalent factors (acted as both inhibitors and facilitators of SDM)		
5	Patient-related factors	Patients' capability to become involved in their care
6	Physician-related factors	Professional attitudes and approaches
		Inviting the patient to participation in DM
7	Overlapping factors related to both patients and physicians	Communication skills
8	Organizational factors	Time during consultation
		Instruments for SDM

## 5. Interpretation and discussion of findings - main points

This chapter presents the discussion and conclusions of the research key findings, the integration and interpretation of the both quantitative and qualitative main findings.

### 5.1 Patients' preferences for involvement in decision-making process (DMP) and the factors affecting these preferences

The results in the present study demonstrated that overall, in the Israeli primary healthcare Colorectal cancer (CRC)-ill patients' preferred a collaborative level of involvement in

treatment decision-making (DM). The value of autonomy has also been demonstrated in the literature in relation to patients' diagnosed with CRC disease preferences for participation in DM. In the study of Hopmans et al. (2015), conducted according to the mixed methods approach, the majority of the CRC-ill patients preferred to make treatment decisions in a collaborative way with their oncologists during the encounters.

The present study also assessed the factors affecting patients' participatory roles in the DMP preferences. Concerning the *socio-demographic factors*, as hypothesized and consistent with other studies (Légaré & Thompson-Leduc, 2014), the results of the present study showed that patients' preference for involvement appeared to be related to *age, education level, employment and origin*. It seemed that younger, more educated, employed and originally from USSR or Israel patients, were more likely to view shared decision-making (SDM) as their preferred style of patient-physician interaction. With regard to *gender*, no differences in patients' preferences for DM roles according to gender were found. This could be correlated with issues such as socioeconomic status and autonomy in personal health matters in Israel. This could be a cohort effect, as in Israel there are no identified gender differences with regard to education level or socioeconomic, compared to other European countries. It can therefore be assumed that in Israel, patients' preferences for decisional roles were homogeneous among men and women.

Concerning the *consultation characteristics*, patients who preferred to participate in DMP, attributed great importance to the *continuity of care with the same physician* as a factor, which had a positive effect on their wish to participate in DMP. 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 to conduct discussions with the physician, on a personal level, which encouraged a more collaborative role preference for patients.

## **Theme 1 - Factors associated with patients' decision-making preferences**

### **Category 1.1 - Patients' perception of sufficient knowledge and information**

The first category, referred to *the importance of information and knowledge about the patients' disease and treatment options, as a factor affecting patients' preferences for participatory role in the DMP*. This category highlighted how socio-demographic factors, such as age, education-level and access to knowledge and medical information could affect patients' preference for decisional role during consultations. Less elderly, young and more educated patients explained that their exposure to and having better technical skills of using various web

databases, provided them with knowledge regarding their illness and treatment options, their rights as patients, and the more modern approaches in healthcare, such as the patient-centered care (PCC) approach. These privileges increased their confidence to engage in the DMP, and to share their knowledge with the physician, in order to be sure in the resulting treatment decision.

As patients' age, they might be more at ease with leaving decisions to their healthcare providers (Ghanea et al., 2014). Ten Klooster et al (2012) also claimed that age and level of education might influence the self-efficacy of patients, as older and less educated patients with cancer frequently suffer from suboptimal physician- patient communication. Older people and less educated patients in general have more difficulties with information storage and retrieval, medical terminology and therefore encounter more medical issues compared to younger and well-educated people. As a result, elderly patients can experience lower self-confidence levels when engaging with physicians and in SDM, and therefore tend to avoid involvement in DM.

The present study quantitative results were supported by the qualitative, demonstrating that one of the possible reasons for patients' preference for the SDM approach was their accessibility to medical knowledge. Based on these findings, in the present study it is suggested that, today, physicians need to be more aware of the new generation of young patients, with all of its aspects of greater access to medical knowledge, better health literacy, technological and communication skills, affecting their abilities to process medical information and engage in treatment DM.

### **Category 1.2 - Social/cultural perception of physicians' authority**

This category deals with patients' *perceptions and beliefs regarding the quality of care provided to them in the social/cultural context*. Patients indicated that their preference to remain passive in the DMP emanated from cultural paradigm, secondary to social differences, due to their traditional approach to physician's status and role in their society, which considered the physicians as "knows best", dictating that the physician should be considered as the highest authority when it comes to medical care. It appeared that patients, who were originally from societies, which were supportive of the paternalistic approach, valuing the elite status of the physician, were more likely to be affected by the perceptions accepted in their social environment.

These findings support the quantitative results of the present study, showing that preference for SDM was associated with patients' *origin*, with the majority of patients who preferred a collaborative decisional role, coming from USSR-Russia or Israel. The present study was

conducted in Israel, where there is heterogeneous population of patients: Jewish, Arabs Muslims and Christians from different origins, regions and cultural background. It seemed that cultural diversity in Israel could affect patients' preferences for involvement in DM.

The present study highlighted that patients' preference for involvement in DMP stemmed from the social-cultural paradigm. These social structures and attitudes might affect patients' view of their role as patients and, as a result, their preferences for involvement in the DMP. Hence, since patients' preferences for participatory positions in DM could be a socially/culturally defined phenomenon, the approach to providing information and assessing the values and desires of patients should be culturally sensitive and take into consideration the cultural diversity.

### **Category 1.3 - Trust in the physician**

The content analysis gave rise to the third category, which referred to the role of patients' *trust in the physician* and valuing the expertise of the physician as a factor affecting patients' preferences for participatory role in the DMP. The content analysis illustrated that patients with lower perceived medical literacy capabilities and communication skills, may perceive higher levels of trust in the oncologists' scope of knowledge and medical judgment. It is evident that the lack of knowledge gave patients less scientific power compared to the oncologist, leading to knowledge gaps between the patient and the oncologist, resulting in more trust in the oncologist's expertise and a preference for a more passive involvement in DM. It seems that patients' higher levels of trust in the physician, due to low health literacy and knowledge, made the patient view the physician as a trustworthy figure, in terms of medical knowledge and professionalism, someone the patient can rely on, enabling the patient to undertake a more passive role in the patient-physician interaction and the DMP.

These insights correlated with the results of the quantitative part of the present study, showing that patients with higher levels of trust in the physician were associated with the preference for the paternalistic approach, and patients, who preferred SDM, reported lower levels of trust in their physician. It seems that, while these higher education and access to knowledge increased patients' confidence in their ability to participate in the DMP, it has also evoked in patients some level of mistrust in the physicians' medical judgment, facilitating their wish to be involved in the DMP.

In line with these findings, Schoenfeld et al. (2019) found that patients who preferred shared roles were less likely to trust the physician. The researchers explained that patients who desired

SDM usually had higher health literacy and access to medical knowledge. In this way, the system of trust between the patient and the physician was based on the patients' perception of their level of knowledge, health literacy and physicians' professional level.

#### **Category 1.4 - Continuity of care with a usual physician**

The fourth category derived from the content analysis, referred to the *nature of the relationship between the patient and the physician*, and its impact on patients' preferences for involvement in DMP. The interviews illustrated that patients attributed great importance to the *continuity of care with the same physician* as a factor, which had a positive effect on their desire to participate in DMP. The continuity of care enabled both the patient and the physician to develop a good and trustful relationship, allowing the patient to feel more comfortable with the physician and easier to open up to physician and express themselves, encouraging patients' preference for SDM. The findings of the present study supported the notion that SDM involved much more than the moment a decision was made, showing that effective patient-physician relationships, based on mutual trust and respect, developed through the continuity of care, was an important contributing factor of patients' involvement in care, as it helped to overcome communication barriers.

These insights explained and expanded the understanding of the quantitative results of the present study, showing that patients who wished for SDM reported having a continuous relationship with their physician, indicating that in the continuity of patient-physician relationship, trust often created an inviting environment for SDM, as it facilitated communication and made patients feel at ease when making discussions with the physician.

A patient's trust in the physician emerged as having a paradoxical role. On the one hand, patients in the present study noted that SDM would be easier with a physician they trusted (due to their continuity of care with the same physician), while on the other, they noted that mistrust in the physician made them want more involvement in DM. An explanation of this paradox can be found in previous studies (Peek et al., 2013), which emphasized the complexity of the concept of trust, arguing that trust can be conceptualized in various ways. These studies described patient's trust as primarily arising from two domains or key areas: one of interpersonal values (respect, communication) and another of technical competence (expertise). The integrated quantitative and qualitative results of the present study also demonstrated that patients who preferred SDM conceptualization of trust, might be different. Those patients, who perceive 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' expertise and knowledge, and what was best for the patients. Joseph-Williams et al. (2014) strengthened this result. The researchers found that patients' mistrust in their physician might potentially be reduced through patient education and improved access to medical information from the internet (i.e. manifestation of medical knowledge/skills), and this might may adversely affect patients' trust in the physician. Conversely, those patients who defined trust as being treated and respected like a person probably mainly addressed the interpersonal conceptualization of trust and, thus, perceived high level of trust. This was due to their continuity of care and familiarity with the oncologist that enabled them to feel comfortable to open up and express their needs and values. In the latter case, trust perceived by patients in an interpersonal-communication context, resulted in patients' trust in the oncologist on a personal level.

### **Category 1.5 - Increasing expectations of healthcare**

This category dealt with *patients' expectation of the quality of care provided to them and the healthcare system, as a factor affecting their preference for involvement in DMP*. This category addressed the qualities of a high standard of care, which patients wished to receive in the 21st century of a modern and patient-oriented healthcare climate. The content analysis illustrated that patients' perceptions regarding quality of care had shifted from a paternalistic to a more patient-centered approach, reflected in their increased expectations from physicians and the healthcare system. The disparity in patients' views could result from a new generation of patients, exposed to more participatory forms of interactions with physicians in the recent past, and having higher standards of communication, which have positively affected their wish for a more shared decisional role. It was evident that patients expected qualities, such as respect, consideration of patients' needs and values, being heard, being treated as a person and not as "another case", to be reflected in the healthcare system for a sensitive population such as oncologic patients.

According to Aminaie et al. (2019), in the late twentieth century and the last two decades, cultural views have changed, usually in developed and modern societies to a more patient-centered model. Along with the shift made by social/cultural structures in developed and advanced countries in the twentieth century, facilitating patients' preference for SDM and patients' expectation from healthcare continues increasing. 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.



## **5.2 The status of SDM and the factors affecting its implementation in the Israeli chronic cancer primary clinical practice**

As hypothesized, the results of the present study demonstrated that only a small number of patients perceived they made treatment decisions in a collaborative way with the oncologist. In addition, as hypothesized, the present study was able to demonstrate relatively low levels of concordance between CRC-ill patients' preferred and actual decisional roles in DMP, indicating that patients preferred more involvement in DM than they actually experienced. This gap between *preferred* and *actual participation* constituted a significant issue in chronic patients' experience of care in primary healthcare environments. It raised the question whether the patients were assessed for their preference for SDM, in order to enhance their level of involvement. It could be a reflection of patients' experience that they had not been assessed with their preferences for involvement in DMP by the oncologists and did not feel supported by them when making the decisions. This implied that predicting patients' role preferences, instead of determining it directly, might lead to miscalculations of patients' desired decisional role, and thus it should be avoided. A screening of the patients' preference could be helpful and could facilitate communication between the clinician and the patient.

The present study also found that SDM approach was applied in daily routine practice with CRC-ill patients to a limited extent only, with the majority of the oncologists, who participated in the present study and provided direct care to CRC-ill patients, were reluctant to involve CRC patients in treatment DM. Some of these oncologists might have been reluctant to report that they genuinely perceived a high level of comfort with the shared approach, and felt comfortable with making decisions in a collaborative way. This raises the question: Why, then, did some of these oncologists not use it in their practice?. There could be situations in which oncologists were forced not to apply the shared approach, with which they felt really comfortable, due to certain constraints.

In order to gain an in depth understanding of the situations in which oncologists are forced not to apply the shared approach, and patients are reluctant to participate in the DMP, semi-structured interviews were conducted with CRC-ill patients and with the physicians. The content analysis obtained from the interviews facilitated a thorough comprehension of the factors affecting the status of SDM in the Israeli primary cancer healthcare, challenges and facilitators on multiple levels of the healthcare system and the Chronic Care Model (CCM).

### **Theme 2 – Patient-related barriers to SDM**

#### **Category 2.1 - Making decisions because of despair**

This category addressed *patients' perceptions of the complexity of the cancer disease and the circumstances with which cancer patients had to deal*. This entailed vulnerability of the cancer patient, making CRC-ill patients feel despair. Thus, they felt pressured to accept the physicians' opinion, limiting the opportunity for SDM. Patients described circumstances in which they felt pressured due to personal despair and fears regarding the disease progression and complications, leading to a feeling that they had no choice but to accept physicians' opinion regarding their treatment, which left little room for SDM. These results were in line with the study of Aminaie et al. (2019), who argued that patients' climate of despair, especially those diagnosed with complex chronic diseases such as cancer, might exacerbate their emotional distress, fear and disrupt their judgment. Consequently, in situations where patients have to deal with decisions which might affect their lives, these emotions force these patients rely on the physicians' opinion, with the perception that physician knows best.

### **Category 2.2 - Exposure to information sources**

This category referred to the oncologists' perceptions of *patients' exposure to multiple medical information sources and databases as a barrier to SDM*. The physicians' statements illustrated that patients' ability to participate in the DMP with the oncologists might be inhibited by their access to multiple information sources, which could not only lead to information overload, but also cause reception of unreliable information. This finding is consistent with Liu & Kuo's (2016), who found that clinically and empirically, physicians commonly fear overloading patients with information, and are concerned about disclosure of multiple treatment options and their risks. Moreover, this phenomenon might in many cases lead physicians to perceive that this kind of patients are not suitable for SDM, as not all patients are able to manage, understand and combine multiple information, which could exacerbate patients' confusion and stress. However, the present study, as well as previous studies (Levy & Janke, 2016), proved that social media and internet were useful platforms for patients' increased knowledge and preparation for the consultations, improving their confidence for care management autonomously. Nevertheless, patients should conduct discussions with physicians regarding this obtained knowledge, in order to compare their knowledge to that of the experts and ensure its reliability. As the physician is considered a reliable source of information, it could be helpful to find the right balance between being under- informed and overloaded with information.

### **Theme 3 – Patient-related facilitators to SDM**

## **Patients' emotional support from family and others**

This category addressed *patients' perceptions of their sources of support*, and highlighted the role of family members and patients' support resources and its significance for facilitating patients' participation in DM. The content analysis illustrated that patients attributed great importance to the support from their family members and friends, and considered it as a meaningful facilitator of SDM. With family's support, patients felt more confident in their ability to participate in DM. Several systemic studies on DM have endorsed the notion that family and social support services are important to the cancer patient and play a key role in cancer treatment, and patient behaviors including DM (Tranberg et al., 2016), as family usually helped patients to facing and solving difficulties, including complex decisions, illness-related issues, demonstrating strong family ties and affection. This reflects the characteristics of the Israeli population culture. In Israel, the availability of support has a considerable impact on treatment DMPs. In the Israeli culture, the institution of family plays a major role over the individual.

## **Theme 4 – Physician-related facilitators to SDM**

### **Category 4.1 - Perceived personal incentives**

This category referred to *oncologists' perceptions regarding the physicians' perceived personal incentives*, which from their point of view might motivate the implementation of SDM in their practice. The findings showed, that physicians considered patients' satisfaction scores as a motivator for applying SDM in their routine practice. It was evident that physicians were motivated by these scores to give patients more than was expected if they wanted to boost their satisfaction ratings. Previous studies (Mathijssen et al., 2020) also confirmed the idea that patients' satisfaction with care was a guiding principle of professional practice. Patients' satisfaction rates were indicated as a factor in sustaining relationships between physicians and patients. It was also one of the professional if not personal rewards of being a healthcare provider.

### **Ambivalent factors**

The content analysis of the data collected through the interviews identified the following themes, *acting as both inhibitors and facilitators of SDM*.

## **Theme 5 – Patient-related ambivalent factors**

### **Category 5.1 - Patients' ability to become involved in their care**

This category addressed *both patients and oncologists' perceptions regarding patients'*

*ability to participate in the DMP*, which acted as both inhibitor and facilitator of SDM.

#### *The oncologists' perspective*

According to the oncologists' perception, patients' physical and psychological health status could inhibit or facilitate their ability to become involved in their own care. SDM might not be in the interests of patients as it generated psychological distress, discomfort and exacerbated phobias in the long term, which could affect the patients' chances of good recovery. Conversely, others considered that patients' emotional readiness is helpful for SDM. These results were in line with the findings of Schildmeijer et al. (2018), who found that that physicians' misconceptions regarding patients' abilities for participation in DM might affect their actual engagement.

#### *Patients' perspective*

Patients' perceptions regarding their ability to be involved in SDM was directly linked to their degree of self-efficacy, derived from baseline information, knowledge, and health literacy, acted as a barrier and facilitator for SDM. These findings supported the findings from the qualitative part, demonstrating that patients' education and perceived knowledge levels, and coping skills were directly related to their decreased self-efficacy regarding their abilities for SDM. Based on the results of this study, the extent to which CRC-ill patients and their oncologists participate in the DMP appeared to depend on how patients viewed their own status or judged their own capacity to participate in the DMP.

## **Theme 6 – Physician-related ambivalent factors**

### **Category 6.1 - Professional attitudes and approaches**

This category referred to the *perceptions of patients regarding the attitudes of professional oncologists towards SDM*, reflected in their behavior during consultations, as a factor affecting their ability to participate in the DMP collaboratively. Several patients perceived the physician as being authoritative and not supportive of the SDM approach, which subsequently had a negative impact on their ability to actively and positively participate in DM. On the other hand, some patients described a more holistic and patient-centered behavior and attitude of the oncologists, who viewed the patient as a person with a narrative, who was active and capable of participating in DM or as equal partner, which encouraged the patients to engage in the DMP. These results are in line with previous studies (O'Malley et al., 2016), which found that the beliefs, attitudes and behavior of healthcare employees, physicians and nurses could have a major effect on patients' participation in DMP. Thus, the present study suggested that physician

support for SDM was necessary for facilitating a meaningful SDM. As physicians in the patient-physician interaction and communication appeared to have more control than patients, it was possible that physician biases and attitudes influenced patient capacity to engage in the DMP.

### **Category 6.2 - Inviting the patient to participate in decision-making**

This category referred to the *oncologists' acknowledgement of patients' option of becoming part of SDM, as perceived by patients* in the present study. Patients highlighted the importance of being acknowledged as partners to the DMP, regardless of their preference. Analytical studies have shown that patients are not invited to participate in DM (Covvey et al., 2019). This reinforces, once more, the present study previous recommendations and conclusion, namely that physician should accurately assess patients' preferences for involvement in DM and should navigate their behavior in the information sharing area respectively.

## **Theme 7 - Overlapping factors related to both patients and physicians**

### **Category 7.1 - Communication skills**

This category indicated *patients' perception regarding both patients and physicians' communication skills required for SDM* as both inhibiting and promoting factor of a successful SDM. The first patients' perspective of patients dealt with their perceptions of the physicians' communicative skills for SDM and how it affected their ability to participate in the DMP. The patients perceived the oncologist's behavior during the encounters as technical, inhibiting the patients' ability to engage in DM. Other patients' words gave rise to another aspect of physicians' lack of communication skills, manifested by the in physicians' dismissiveness and inattentiveness regarding the patients' opinions. They indicated that the oncologist was dismissive of the medical knowledge they brought to the encounter. Another aspect of physicians' lack of communication skills, reflected by the patients' feeling of inability to understand the information received from the physician, due to its complexity or the use of difficult Latin medical terms. It is clear that patients' participation in DM depended on patients and physicians' capability to achieve a favorable physician-patient communication.

## **Theme 8 - Organizational factors**

### **Category 8.1 - Time during consultation**

This category *addressed both patients and oncologists' perceptions regarding the factor of time during consultations, and the way it affected patients' engagement in DM*, which perceived by the participants as both inhibiting and promoting factor of SDM.

### *Patients' perspective*

Patient considered the sufficient time factor as significant in the success of the SDM approach during encounters, since could enable the application of SDM principles properly.

### *Oncologists' perspective*

According to the oncologists in this study, time with a patient during medical examination was critical for effectively applying the principles of SDM in practice. The preventive effect of insufficient time during consultations on oncologists' ability to engage CRC-ill patients in DMP was reflected in oncologists' acknowledgment that shortage of time made it difficult to develop trustful relationships with the patients and address all questions and concerns. Time constraints were directly related to high workload, pressure, and high expectations of the Israeli healthcare system, which evoked their emotional distress and inability to apply SDM principles in practice. On the other hand, few oncologists indicated the facilitative effect of sufficient time during consultations for the success of SDM. Consistent with previous scientific evidence, researchers (Hayes et al., 2018) stipulated that a proper SDM process take time and requires at least half an hour, which is also essential for relationship and effective communication building, which were an important factor in SDM.

### **Category 8.2 - Instruments for SDM**

This category referred to the *instruments for SDM, provided to oncologists by the healthcare system and the medical organizations*. These instruments, such as education of clinical, interpersonal, and communication skills, a role model of medical instructors, assessment system for monitoring SDM, as well as guidelines and protocols for SDM application were discussed by the oncologists in the present study as factors of great importance for the implementation of the SDM approach in their practice. This issue was also confirmed by previous studies (Rashidian et al., 2013), claiming that SDM was not an inborn talent but consisted of specific behaviors that could be taught. Other previous studies (Covvey et al., 2019), also found that teaching physicians about SDM could lead to improved staff communication skills and increase patients' collaborative role in DM. Therefore, in addition to the formal theoretical training, provided to medical students, in the field of ethics and SDM, it was strongly recommended that their communication skills, knowledge of the SDM principles and guidelines for implementing this approach be practically strengthened in order to establish better relations with patients.

### **5.3 The effect of SDM on chronic patients' health outcomes**

The present study illustrated that CRC-ill patients, who perceived their participation in DM as shared and were more *satisfied* with the care received from the oncologist, were more likely to comply with treatment recommendations, perceived better capability to manage their cancer disease, and were less anxious or depressed. In line with the results of the present study, previous scientific evidence (Lin et al., 2019) suggested that different areas of SDM could increase patient satisfaction with the care received and their experience during the encounter and the treatment received. With regard to patients' treatment compliance, the results of the present study were in line with the Hughes et al. (2013) systematic review among chronic patients found that the most frequently reported reasons for patients' improved compliance were that patients' participation in the DM enhanced their sense of commitment to the decision, and allowed to obtain more information and knowledge regarding their treatment.

With accordance to the literature and the findings of the present study, SDM might serve as a proxy for patients' behavioral change in the improved ability to manage their chronic condition, developing better self-care skills and increasing their autonomy in self-management. In order to achieve patients' control over their disease, develop a more autonomous behavior and better skills for managing their disease, greater knowledge and confidence in their ability to adopt this behavior were needed. Results of the present study demonstrated that this could be achieved through the process of SDM, as it might generate patients' knowledge regarding their disease and treatment options, and increase their self-efficacy in their ability to manage their disease independently.

The findings of the present study regarding the effect of SDM patients' knowledge about their care and health literacy warranted a closer look. One of the most beneficial effects of SDM was its impact on patients' improved knowledge and increased self-efficacy as a proxy for other health behavior changes, such as improved compliance with treatment and management of chronic condition, developing better self-care skills and increasing their autonomy in self-management, and, thus, achieving a better control over their disease.

## **6. Conclusions and recommendations**

### **6.1 Factual conclusions**

The result of the present study confirmed that there was a need to increase participation in the decision-making process (DMP) for colorectal cancer (CRC)-ill patients. Oncologists and healthcare organizations should strive for shared decision-making (SDM), and apply strategies for facilitating this process in chronic care practice, where patients are supported by exploring their needs and contributing their expertise to the conversation.

Furthermore, the present research has provided additional knowledge and understanding about the predictors of patients' preferences for engagement in the DMP and, subsequently, to the identification of potential approaches to promote patient involvement in decision-making (DM). By understanding the typology of patient preferences for participatory roles in DM, healthcare providers would find it easier to promote SDM application in practice.

The findings of the present study illustrated that patients' socio-demographic background and personal characteristics, such as the need for information and trust in the physician, played a significant role in their preferences for involvement in the DMP, since it directly affected patients' perceived applicability and self-efficacy for participation. The present study also highlighted that patients' preference for involvement in DMP emanated from the social-cultural paradigm. Society and culture might dictate patients' perceptions of physicians' status and authority from the traditional medical dominance supporting power distance and hierarchy in patient-physician relationship in favor of the physician. These social structures and attitudes may affect the vision of patients regarding their role as patients during the meetings and their preferences for participation in the DMP. The results of this study suggested that departure from conventional patient-physicist roles would be correlated with social and cultural changes in behaviors and attitudes among patients. Hence, the approach to providing information and evaluating patients' values and wishes should be culturally sensitive and consider cultural diversity.

The present study also confirmed that cancer-ill patients' involvement in their care was essential not only for patients' wellbeing, but also for better health outcomes, the physicians and the healthcare system. One of the most beneficial effects of SDM was its impact on patients' improved knowledge and increased self-efficacy as a proxy for other health behavior changes, such as improved compliance with treatment and management of chronic condition. Patients developed better self-care skills and increased their autonomy in self-management, attaining better control over their disease.

The present study provided useful first steps for understanding the perspectives of the most important stakeholders in SDM (i.e. the physicians and patients - the players in the DMP) with regard to their perceived inhibitors and facilitators of SDM engagement in chronic care. These inhibitors largely acted as facilitators as well, tending to depend on the initiatives, beliefs, personal and social/cultural perceptions and values of individual patients and physicians, as well as on organizational support level. These results suggested approaches by which SDM could be further implemented into chronic cancer care. The success of SDM would require proactively addressing the clear and accurate knowledge and tailor-made education,



instruments for SDM implementation in practice, appreciation for multicultural values and needs of patients, as well as emotional support are strategies for enhancing patient-centered treatment. Patient and physician training programs and instructional resources may help patients and health care providers make SDM a routine component of Patient Centered Care (PCC).

### **Compatibility and relevance of SDM in the Israeli primary healthcare culture in management of chronic conditions.**

The Israeli universal and modern healthcare system already has the infrastructure necessary for incorporating SDM in clinics and hospitals on a national basis. It would seem that the universal and progressive healthcare system in Israel provides an environment that is consistent with patients' choice options and future empowerment (The society for Patients' Rights in Israel [SPRI], 2012). However, much more is needed. There are clear evidence gaps that deserve further attention. For example, it is necessary to invest more in the development of continuous training for physicians in order to improve their applicability for SDM. They should modify their perceptions through multiple avenues including comprehensive undergraduate education across all university medical, continuing education across different fields, and using evaluation methods in the various Health Maintenance Organizations (HMOs).

## **6.2 Conceptual Conclusions**

The present study demonstrated the conceptual framework for a higher-quality cancer care system, which highlighted the importance of the involvement of cancer patients in DMPs as a way to PCC and improve communication and health outcomes. Such a system should support patients at the center of the care provided, in line with their needs, values and preferences, and ensure that these principles guide clinical chronic care DM. This model is integrative in that it requires and emphasizes the relationship between all the parties involved in SDM: the patient, the physician, the primary healthcare facilities and the healthcare system. These dynamically interact in order to affect SDM implementation in chronic practice, which is in line with the concept of PCC.

Four main concepts and factors were at the center of the conceptual framework for improving SDM implementation, as perceived by both patients and physicians in the present study: (1) patient-physician relationship; (2) patient/physicians' perceptions, attitudes and behaviors towards SDM; (3) patients' preferences for involvement (motivation; and (4) healthcare system (organizational) factors. These concepts, which were related to and affected each other,

provided insights regarding the efforts and strategies required for SDM implementation in the Israeli practice.

## **7. The contribution of the present study**

### **7.1 Contribution to theoretical knowledge**

The present study made useful contributions to two theories and models of improving chronic patients' quality of care and management of their disease - The Chronic Care Model (CCM) (Davy et al., 2015) and the Model of PCC (Epstein & Street, 2011). The results of the present study confirmed the relevance these theories' concepts to shared decision-making (SDM), as a means for improving chronic quality of care.

Moreover, the present study contributed to the literature and research, as it expanded the existing body of knowledge regarding the factors involved in the decision-making process (DMP) in chronic healthcare. It demonstrated how each factor of the conceptual framework, separately and in an integrative way, helped in facilitating the SDM approach in chronic healthcare, in Israel.

### **7.2 Contribution to practical knowledge - Practical implications and recommendations**

In light of the present study results, there were important practice implications for patient centered care (PCC) delivery and improved quality of care. To turn SDM in cancer care into a practical reality, tailor-made implementation strategies targeting factors related to all levels of the healthcare system were needed. Addressing the individual and combined impact of various barriers to evidence-based decision-making (DM) in Israel, possibly involving multi-faceted approaches, ranging from patient and physician education and training programs on the principles of SDM and recommendations for its implementation, through strengthening the communication skills, to promoting tools to improve the nature of clinical workflows in chronic health facilities.

## **8. Strengths and limitations of the present study**

The present study has several strengths and limitations, which need to be considered. One of the strengths resides in its mixed methods approach. The present study integrated quantitative and qualitative methods, which allowed for a more comprehensive assessment of the factors involved in the decision-making processes (DMPs) in chronic care framework, compared to one research method only.

However, the present study should also be considered in light of several limitations. One of

the research limitations was the recruitment of patients. The present study was conducted in a single out of four Health Maintenance Organizations (HMOs) in Israel. Thus, the option of generalizing the results to the entire Israeli primary healthcare might be questioned. Interpretation of the findings should, therefore, be taken with caution. Thus, a multi health center study is needed to confirm the results of the present study and to assess other contributing factors related to patients' participation in shared decision-making (SDM).

The second limitation was no assessment was made of the patients' health-related factors, which, according to the medical literature, might affect patients' preferences for level of involvement in the DMP. The present study addressed only a single type of cancer, without addressing other types of cancer neither the stage of the colorectal cancer (CRC) disease, as factors affecting patients' preferences, which might limit the generalizability of the results of the present study to other types of cancer-ill patient groups and to different stages of the CRC disease.

## **9. Recommendations for future research**

The insights of the present study were also relevant for future research. First, in order to understand better the issue of the proper application of all shared decision-making (SDM) steps and the mechanisms of SDM during consultation on cancer treatment, it is recommended that an interactionist approach be followed in the future studies to explore patient-physician conversations objectively, identifying the experienced involvement of chronic patients in each step of the SDM process and not just the final step of making the actual treatment decision. It is also recommended conducting a future survey that will focus on a wider longitudinal approach, documenting multiple oncologist visits rather than just one. The second recommendation of the present study is to investigate other types of cancer, finding out additional factors involved in patients' decision-making (DM) attitudes, preferences and behaviors.

Additionally, it is highly recommend exploring additional outcomes of the SDM implementation in the Israeli healthcare system, including patients' safety, and the prevention of medical errors, as well as physicians' satisfaction. Furthermore, future studies are recommended, especially in areas related to patients' awareness of their rights in the DM as well as physicians' awareness of the patient centered care (PCC). These next steps in future research might be helpful in deepening our understanding about the complex nature of healthcare DM in chronic practice.

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## **List of abbreviations and acronyms**

API	Autonomy Preference Index
CCM	Chronic Care Model
CPS	Control Preference Scale
CRC	Colorectal Cancer
CQR	Compliance Questionnaire for Rheumatology
DM	Decision Making
DMP	Decision Making Process
IDM	Informed Decision Making
HAADS	Hospital Anxiety and Depression Scale
HMO	Health Maintenance Organization
PCC	Patient Centered Care
PSQ	Patient Satisfaction Questionnaire
SDM	Shared Decision Making