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Articles

Treatment decision-making process of men with newly diagnosed localized prostate cancer: the role of multidisciplinary approach in patient engagement

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Abstract

The diagnosis of prostate cancer (PCa) often represents a stressful event. In addition to the psychological distress related to the diagnosis, patients face challenging health decisions: in fact, besides radical treatments, Active Surveillance may represent an option for patients with diagnosis of localized PCa. A multidisciplinary clinical approach seems to represent the suitable organizational model to meet such a requirement, optimising the therapeutic outcome for PCa patients. The present study is a qualitative examination of the treatment decision-making process of men with a newly diagnosed localized PCa who received a multidisciplinary clinical consultation. Results suggest that a multidisciplinary approach may satisfy patients' need to be comprehensively informed about all their chances and options of curing and managing the disease. Together with information, patients need to build a therapeutic relationship with the physicians in order to share their treatment decision-making experience. If this does not occur, frustration, confusion and other negative emotions may emerge.

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1. Introduction

The diagnosis of Prostate Cancer (PCa) represents a stressful event. In addition to the psychological distress related to the diagnosis, patients often face challenging health decisions in a context of great uncertainty. In fact, they unexpectedly deal with the opportunity/burden of choosing among multiple strategies that have comparable curative efficacy but differ in terms of clinical and personal costs and benefits (Cooperberg et al., 2011; Klotz et al. 2012; Heidenreich et al., 2014).

For patients with clinically localized PCa, besides radical treatments (i.e., radical prostatectomy, external beam radiotherapy, brachytherapy, combined or not with hormonal

therapy), Active Surveillance (AS) may represent an option. Considering this scenario, high levels of decision-related distress at the time of diagnosis are common. A first step to support patients' in overcoming decisional conflict consists in providing comprehensive and balanced information about the care process, the therapeutic options and all the relevant associated advantages and risks.

A multidisciplinary (MD) clinical approach seems to represent the suitable organizational model to meet such a requirement, optimising the therapeutic outcome for PCa patients (Ko & Chaudhry, 2002; Kagan, 2005; Gomella, 2011; Aizer et al., 2012; Gomella, 2012).

Despite the advantages of MD models have been acknowledged, their implementation is still facing a number of barriers from both an organizational and cultural perspective (Valdagni et al., 2011) and patients' perception is still not evaluated (Lamb et al., 2013).

With the aim of providing feedback and guidance to health care professionals, the current study intended to explore the treatment decision-making process of men with a newly diagnosed localized PCa who received an MD clinical consultation.

2. Materials and method

The present study is a qualitative examination of the treatment decision-making process of men with a newly diagnosed localized PCa who received an MD clinical consultation (the Prostate Cancer Unit at Fondazione IRCCS Istituto Nazionale dei Tumori in Milan). Patients who had previously received treatment for PCa or patients with a new diagnosis of locally advanced or metastatic cancer were excluded. During the MD visit (MDV) (Magnani et al., 2012) patients contextually met a urologist, a radiation oncologist and a psychologist.

The physicians recorded the medical history, performed a digital rectal examination and informed the patients and their families about the feasible radical/observational options; a psychologist monitored the potential sources of psychological distress and presented the opportunity of a path of psychological counselling. At the end of the MDV, patients were informed about the decision-making study and invited to participate. Patients who accepted were immediately interviewed in a separate room, after they had signed an informed consent.

Given the exploratory nature of the study a semi-structure interview was developed on the basis of the standard template from the Ottawa Decision Support Framework (O'Connor et al., 2011). As shown in Table 1, ten men (age range: 54-72, mean = 64.8, SD = 5.6 years) with localized PCa were interviewed by two psychologists with competencies both in

clinical/health and research psychology; the interview lasted 27 minutes on average (range 17-40 minutes).

They were recruited by theoretical sampling; this kind of sampling, regulated by the emerging theory, consists in identifying subjects following the indications coming from analysis process (Tarozzi, 2008), deepening the emerged dimensions step by step in order to verify the capacity in different contexts; the enlargement of the sampling is interrupted when all the emerged categories are considered saturated, in this case after 10 interviews.

Table 1. Demographic/clinical characteristics of the sample and therapeutic/observational options proposed before and at the MDV.

ID	Age	Marital status	Educational level	Employment	Disease risk classification	Therapeutic option suggested before the MDV ¹	Therapeutic option suggested at the MDV
ID 1	54	Divorced	Degree	Entrepreneur	LOW	RP	RP, EBRT, BT
ID 2	69	Married	High school diploma	Employee	LOW	RP, EBRT	RP, EBRT, BT, AS
ID 3	58	Married	Degree	Entrepreneur	INTERMEDIATE	RP, EBRT, BT, AS	RP, EBRT, BT
ID 4	66	Single	High school diploma	Employee	LOW	/	RP, EBRT, BT, AS
ID 5	70	Married	Secondary school diploma	Pensioner	HIGH FOR PSA	/	RP, EBRT+HT
ID 6	64	Married	High school diploma	Entrepreneur	LOW	AS	EBRT, AS
ID 7	63	Married	High school diploma	Employee	INTERMEDIATE FOR PSA	RP, EBRT, HIFU	RP, EBRT
ID 8	62	Married	High school diploma	Employee	INTERMEDIATE	RP	RP, EBRT
ID 9	72	Widower	Primary school diploma	Pensioner	LOW	AS	EBRT, AS
ID 10	69	Married	Secondary school diploma	Pensioner	LOW	RP	RP, EBRT, BT

The Framework Analysis (Ritchie et al., 2013) was adopted to analyse the data. A paper-and-pencil method was used to carry out the analysis following specific steps: a) transcription; b) familiarisation with the interviews; c) coding; d) identifying a thematic framework; e) applying the thematic framework; f) charting data into the framework matrix; g) interpreting the data.

¹ RP = Radical Prostatectomy; EBRT = External Beam Radiotherapy; BT = Brachytherapy; AS = Active Surveillance; HIFU = High Intensity Focused Ultrasound; HT = Hormone Therapy

3. Results

Based on the Framework Analysis, four central themes related to the patients' needs were identified.

Theme 1: "The comfort of MD setting". Most patients described they benefited from the MDV in terms of received information from both a qualitative and quantitative perspective. The MDV contributed to clarify the characteristics of their disease, all the therapeutic options they could choose among (*"Until this morning, we had not received any explanation about radiotherapy"; int. 3*). Patients mostly perceived an improvement in the level of knowledge they had before accessing the visit. This perception contributed to generate pleasant emotions such as satisfaction, a sense of personal competence and relief (*"When someone fully explained the situation, they allow you to make a decision that is the best for you. Maybe you could make a mistake, but you get wrong being well-informed of all the available options. So in a such case you say It's ok!"; int.10*.)

Theme 2: "The disadvantage of MD setting". The lack of congruence between the information that most patients received by previously consulted clinicians and the one they were given by the MD team contributed to complicate the individual decision-making process. Most interviewees attending the MDV were searching for a second consultation and often the information and treatment recommendations presented during the MDV were different from what they have received. Following this incongruence, interviewees often reported a feeling of confusion due to the difficulty of processing the new information (*"I'm a little confused, bewildered. At first, I was a bit more keen on surgery, but I didn't know about the third option yet, that is active surveillance, because other physicians hadn't recommended it! Only this time this option, I didn't think about, has emerged"; int. 3*).

Theme 3: "The lack of details". This theme refers to a few unresolved questions about treatment procedures and related side effects that patients felt to still have at the end of the MDV. Some patients would have desired that physicians had provided them with more specific information about the side effects associated with each treatment. On the contrary such an expectation was not satisfied. From the patients' point of view, this contributed to generate a feeling of uncertainty and increase the complexity of the decision-making process (*"The information was not completely detailed, and therefore one cannot evaluate it, think about it and then ask further specifics"; int.10; "I'd like to have more objective data, a percentage of risk and benefits for each option. I know that nobody has the crystal ball, but tell me if there is fifty percent, thirty percent. You know, the numbers help you get an idea", int.1*). When discussing with the interviewees the issue of missing information, two prevalent kinds of arguments emerged. Some participants realised that they did not sufficiently engage during the MDV in the process of sharing their doubt or

questions with the medical team and played a passive role. Other men stressed that they would have liked more time to spend in discussing the provided information with the medical team. Time constraints were referred to as a limit of the MDV by some interviewees which prevented them from organizing the information in their mind and taking time to ask questions and clarify doubts.

Theme 4: “The search for sharing”. This theme refers to the need of sharing their illness-related experience and of feeling of support from others. An important role in the patient’s decision-making process was referred to be played by the spouses who were described as a source of both emotional and material (namely organizational) support (*“My wife will be inclined for the solution that will have a higher percentage of success and will leave us a better quality of life. That’s for sure!”*, int.1). However, in some cases, the familiar support represented a distress factor for men. In fact, the way the partners reacted to their husband’s disease was sometimes reported to affect the men’s mood negatively (*“I don’t know which kind of support I could find in them [...], given my wife has a particular character, I worry for her. She is vulnerable. Int.6)*.

Patients also disclosed to consider the participation of the physicians in their decision-making process as paramount. Overall, the interviewees expressed the desire to feel in relation with the physicians and share with them the decisional process. (*“People who are in our situation have a hundred questions and see the physician as a person who has the knowledge, who knows what can happen! They have expertise and more information than us. So they can give some advice”*, int.1).

4. Discussion

The present study intended to explore the treatment decision-making process of men with a newly diagnosed localized PCa who received a clinical consultation within a MD cancer service. The results highlight the strengths and the limits of a MD context of care as well as the barriers to a shared choice according to the patients’ perspective.

Communication with physicians both in terms of adequate and comprehensive information represents a milestone in patients’ decision-making process. Our results suggest that patients felt to benefit from the MDV in terms of being informed of all the available treatment options. The broad discussion regarding all the appropriate alternatives for managing their cancer contributed to reassure patients and create a greater feeling of hope about the chance of cure and the possibility of protecting their own quality of life. The presence of more specialists in the MDV was considered by the patients as a facilitating element of treatment decision-making since it enabled to overcome the drawback often related to the mono-

specialist visit where physician tends to recommend the therapy within one's speciality (Fowler et al., 2000; Hoffman et al., 2014).

Patients recognized that being presented with a wider range of therapeutic options by the MD team was an opportunity. Nonetheless, they had difficulty processing new information due to a proactive interference effect (Jacoby et al., 2001) which required them some effort of being able to reduce the cognitive dissonance among contrasting information previously received (Festinger, 1957).

Furthermore, the communication process was complicated in some cases by a lack of shared understanding of the clinical evidence; in fact clinicians usually consider risk information in terms of probabilities applicable to populations, not individual patients (Lipkus, 2007). On the other hand, patients' understandings are idiosyncratic and based on subjective experiences or "common sense" which may determine an inappropriate use of health information (Kowalkowski et al., 2012; Coulter, 2010; Denberg et al., 2006; Birnie & Robinson, 2010).

In this sense, a number of decisional aids (DAs) have been developed in order to provide clear and well structured information. External memory supports have been recommended as helpful to support physicians to address patients' comprehension (Peters et al., 2008). Moreover, DAs aimed to help patients identify which questions they would like to be answered before accessing the medical consultation have been shown to be effective. They proved to increase both patients' confidence to successfully make decisions and certainty that they had made the right decision (Hacking et al., 2013). In concordance with this, our MD group adopted a specific information booklet and ad hoc designed brochure reporting the details of what patients should expect from MDV (common needs, therapeutic options, research...).

Nonetheless, we collected evidence that the information alone is not enough.

Our interviewees showed not only do they want to be informed, rather to be guided in navigating the foreign territory of the disease (Rolland, 1999). Many interviewees emphasised a personal need, not completely met, of sharing their treatment decision-making experience with physicians and being engaged during the clinical encounter in a two-way communication process. The experience reported by our patients about their treatment decisional needs are consistent with the increasing consensus for a "shared decision-making approach" (Coulter & Collins, 2011) and suggest that encouraging participation may be the safest standard approach. Sharing the decision-making process means that patients and physicians work in partnership through a two-way exchange of information. They share the responsibility of both offering

and requesting information based on the assumptions that “it takes two to tango” (Charles et al., 1997).

Studies showed that when patients make their decision about treatment in a context where the individual needs and preferences are at the centre of care they are also more likely to trust their clinicians (Keating et al., 2002) and more likely to adhere to treatment recommendations (Haynes et al., 2008), with a view to activate the patient engagement process, crucial component of high-quality healthcare services (Forbat et al., 2009). Specific decision support tools may facilitate shared decision-making, but alone they do not guarantee that it will occur. Shared decision-making may occur in a setting where patients are allowed and supported to have a more active role. If the physician is not motivated to share decision-making, the patient cannot force this to happen. Whether the clinician has a positive attitude toward a shared decision-making approach and prefers decision aids that engage in a shared decision-making process, patients become gradually confident in their ability to enrol in this process with them (Légaré & Thompson-Leduc, 2014).

Patients often feel vulnerable and dependent in the relationship with physicians. (Roter, 1977; Roter, 1984; Kinnersley et al., 2008; Frosch et al., 2012; Henselmans et al., 2012). Clinicians’ attitude plays a crucial role in allowing the patient to gain self-confidence in asking questions, to feel listened, to be engaged in an open discussion where he can have an active role as far as managing their disease and, when necessary, to be helped to correct misconceptions or address any gaps in one's knowledge (Epstein & Street Jr, 2007).

Up to now, the shared decision-making approach has been assessed mainly in mono-specialized context. Very few studies on team-based approaches to shared decision-making have been conducted. Its implementation in a MD context could result extremely challenging given the number of different actors that are involved. Despite working in a MD group was reported to be advantageous as far as providing comprehensive information to the patients and their families, clinicians may be unfamiliar with establishing trust and granting an adequate amount of time to patients and their families in a MD setting (Bellardita et al., 2011) as well as conflicts about leadership may hinder the effectiveness of the team communication (Haward et al., 2003). Training on teamwork and leadership may be necessary to promote good communication among clinical team members and improve their effectiveness in building a relationship with patients in the MD setting.

To our knowledge, this study is the first to explore the met and unmet treatment decision-making needs of patients with PCa accessing a MD cancer service. Particularly, our data suggest that a MD approach may satisfy patients’ need to be comprehensively informed about

all their chances of curing and managing the disease. Together with information, patients need to build a therapeutic relationship with the physicians in order to share their treatment decision-making experience. If this does not occur, frustration, confusion and other negative emotions may emerge.

The identification of met and unmet needs may be useful in facilitating future planning of MD setting from an organizational perspective, including educational and psychological support interventions. Shared decision-making approach had to be further accepted and implemented and specific training to physicians may be necessary.

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