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PATIENT-PATHOLOGIST CONSULTATION; PERCEPTION OF PATIENTS AND THEIR RELATIVES

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ABSTRACT

Introduction: Pathologists' diagnosis frequently have a life changing impact on patients and their families. In this era of precision medicine and individualized therapy, we pathologists have a nondelegable responsibility to re-establish ourselves not just as "doctor's doctor" but as a "patient's doctor." Pathologist –Patient consultation is not new. Patient Pathology consult programmes have been established in many centres across the world. **Aims and Objectives:** To conduct a survey of patients perception regarding pathologist patient consultation. **Materials and Methods:** Survey methodology based on cross sectional study of the population was conducted for the patients/relatives who came for pathologist consultation for a period 6 months. Survey results were analysed using the 'top-box' scoring method which evaluates the percentage of responses selecting strongly agree to strongly disagree questionnaire. **Results:** A total 20 pathologist –patient consultations were recorded by the survey. All patients had undergone FNAC of different organs. All participants answered score 5(strongly agree) and 4 (agree) for the questions on time given, language used, understanding the disease and recommending this program to others. A score of 3(neither agree nor disagree) was given by 20% of the responders for the question on repeat session. For a descriptive question on the most memorable part, many of them wrote "reassurance provided", **Conclusion**: This type of service will make pathologist more visible as she/he is also a part of the cancer/disease care team which in future will help to establish a Formal Patient –Pathologist consult service in the hospital.

KEYWORDS: Patient pathologist consultation, FNAC.

INTRODUCTION

Pathologists evaluate human disease and teach medical students, residents and clinicians. Pathologists are active partners with other physicians, including interventional radiologists to best assure that adequate tissue is obtained for all diagnostic modalities which help in personalized therapy. Today's patients are e-patients. They are tech savy and social media friendly. They google about their disease and the reports. However Histopathology and cytology reports can be overwhelming. In this era of precision medicine and targeted therapy, Pathologists play an important role. Time to change from Doctor's Doctor to Patient's Doctor. Patient- Pathologist consultation is a way forward.

Traditionally, Patient –Pathologist consultations have been infrequent. However, these days many educated patients ask for consultation while collecting their FNAC/ biopsy report which range from 1-2 consultations per month. Author(1) has been conducting these consultations mainly for FNAC (Fine Needle Aspiration Cytology) patients and their relatives for more than two decades. These consultations are neither streamlined nor in an appropriate manner. On coming across a journal article which was discussed as an academic exercise for postgraduate teaching, authors were inspired to conduct this study.[1] To the best of our knowledge this is first study conducted in India and it can serve as a pilot study to start a formal Patient-Patient Consultation service in this hospital.

OBJECTIVES: To conduct a survey of patients perception regarding 'Patient –Pathologist consultation' in a Medical College Hospital.

MATERIALS AND METHODS

Survey methodology based on cross sectional study of the population was conducted for the patients/relatives who came for pathologist consultation for a period 6 months. Survey results were analysed using the 'top-box' scoring method which evaluates the percentage of responses ranging from strongly agree to strongly disagree questionnaire. Study was approved by institutional ethical committee.

The usual method followed for a pathologist patient consult is as follows

- **Preparation**

An appointment is fixed with the help of the laboratory / nursing/clerical staff or the patients themselves.

Following this, the patient with/without a bystander is escorted to the Pathologist's consultation room. Initial identification, obtaining consent and retrieving the slides and reports approximately takes 15 minutes. Additional consent from the patient to include the bystanders is also taken and these individuals are identified and documented. The consult is scheduled during working hours depending on the requirement of the patient.

- **CONSULTATION**

This process takes about 30 minutes, in total. Patients are asked if they have any questions about their disease or what they intend to know from this visit. The consultation proceeds accordingly. If the patient wishes to see the slides, they are shown the same on a multi-head microscope. Normal structures are shown in order to aid with a comparison. As much as possible, it is explained in non-medical language. Patients are permitted to write down the details, if they wish to do so. Patients are not permitted to do videography/photography. Any questions regarding surgery or treatment are deferred to the treating physician

Survey

The patient/ bystander who comes to discuss the report with pathologist is given a feedback form to fill and drop it in a feedback box or handover it. The feedback form is based on the Likert 5-point scoring scale. Questionnare is as given below[1]

1. Was the time given enough to address your concerns?.
2. Was the discussion and explanation of your reports in a language that was easily understandable by you?
3. Were you able to understand your disease better after discussion or viewing your slides?
4. As you have "seen your disease", do you feel empowered and enabled to tackle your disease in a better manner?
5. Would you like to schedule multiple sessions of this programme as a part of your treatment protocol?
6. Would you recommend this programme to someone you know?

What was the most memorable part of this meeting? ……..

Do you have any additional suggestion/comments to help us improve the patient experience in this process? ……..

RESULTS

A total of 20 Patient-Pathologist consultations were recorded by the survey. All the patients had undergone FNAC. Age ranged from 15 to 65 years. Majority were females. (M:F=9:1). Organwise, Breast- 10; Thyroid-4; Lymph node-4, others-2. One had FNAC from 3 sites. Ten had their bystanders accompanying them for pathologist consultation. Twelve of the patients or their bystanders were connected to the institution by way of employment or studies. Three had benign tumour, 5 had malignant tumour report on FNAC. Twelve (12) had non- neoplastic lesions. Summary of the answers to the questionnaire is given in the table 1. Ten(10) respondents (Patients or their relatives) with the medical background or science background were interested in visualizing slides under the microscope. Remaining were explained with the help of pen and paper or computer screen.

Selected responses for free text questions are shown in the table 2.

DISCUSSION

Pathologists are considered as doctor's doctor as they communicate the report to the treating physicians who in turn communicate to the patient. Pathologists also guide the clinicians on, choice of tests, sample collection, preservation and transport for special tests, interpretation of certain rare findings and follow up tests. It is a general practice of clinicians to say that the report is awaited from the laboratory which is perceived by the public as generated from machines. Moreover surgical pathologists rarely felt the need to interact directly with patients as most of clinical information was provided in the request form or available in the hospital information system. Consulting a patient meant additional work for no additional financial gain. With multitasking of academic, research and diagnostic work, pathologists focus most of their time with the glass slides rather than with patients.

With the advent of immunohistochemistry, molecular diagnosis and targeted therapy, Pathologists are actively involved in making an accurate diagnosis for a patient, yet Patients or the public rarely know that there are specialists working to generate the diagnosis. Majority of the printed reports are self explanatory with the diagnosis and suggestions for further treatment. Clinician acts as an intermediary here with an invisible pathologist whose name sometimes not seen in the report. However in this era of expanding and advanced healthcare systems with complex diagnostic tests, clinicians are finding it difficult to stay updated in laboratory medicine and on choice of tests or interpretation. One survey of laboratory utilization patterns revealed that primary care physicians were uncertain of up to 23% of tests utilized, with test ordering uncertainty in 14.7% and test interpretation uncertainty in 8.3%.[2] Nowadays, many of the hospitals provide reports on their online portal. Moreover todays' patients are social media friendly and they browse about their diagnosis immediately and vast amount of information is available which can be overwhelming especially on cytopathology and histopathology reports. This has provided opportunities for patients to discuss with the pathologist who has signed the report. Aquino AC, remarked in her article that the patients who google about their disease come to consult pathologist to know and see their disease rather than finding faults in diagnosis.[3] At this point, pathologists should embrace patient consultation.

Patient –Pathologist consultation is not new. Spencer Nadler has written about this unusual relationship: 'the pathologist- patient relationship' in his book "Language of cells; Life as seen Under the microscope".[4] An internet site entitled "The FAQ (Frequently Asked Question) Initiative: Understanding Your Surgical Pathology Report." is active till date, was created as an outcome of 'Sirmione group' meeting led by Dr Juan Rosai, a leading surgical pathologist in Northern Italy in 2008.[5] Having experienced the benefits of direct communication between patients and pathologists, this meeting was organized by Dr Rosai himself. Guttman E J recalls an incident which he witnessed a decade earlier where an entire farmer family was seeing cancer slides of head of their family on penta head microscope.[6] Guttman also writes about interviewing Vincent A. Memoli, M.D., a general surgical pathologist at Dartmouth-Hitchcock Medical Center, and Andrew E. Rosenberg, M.D., chief of bone and soft tissue pathology at Massachusetts General Hospital. Each have discussed pathologic findings with more than 100 patients at their respective institutions. College of American Pathologists also tells pathologists to be visible, so they participate in various conferences, go for lab rounds, go to all meetings and even interact with patients.[7] CAP has sponsored ' See, Test, and care program'. Social media initiatives on Facebook, Twitter, Instagram and others have created platforms where patients can interact with pathologists.[8] Patient -Pathology consult programmes have been established in many centres like Duke University (Durham, North Carolina) and Lowell General Hospital, Massachusetts. Booth et al report setting up of a Novel Pathologist –patient consult progarmme in Lowell General Hospital and report of outcome of this service.[1]

This study was done on the patients and their relatives who had come for consultation on their own and informally. No consultation fee was collected. In general, patients or their relatives decide to seek information on their own. Typically the diagnosis is read from the report as they collect from the laboratory dispatch counter or revealed by the clinician.

Majority of the respondents were females. Sixty percent were either employed or had their relatives as doctors, nurses, technitians or students of the institution. Similar experience was shared by Dr Memoli.[6] The fact that remaining were not connected to the institutions, speaks about the awareness and desire to discuss the disease or reports with the pathologist. Majority of the respondents answered strongly agree and agree for most of the questions. Seventy five percentage(75%) of the respondents answered strongly agree to the question on time given address and language used to explain their concern. 80% responded strongly to recommend this type of service to others. Findings of our study are comparable to the findings of Booth et al.[1] Answers to the free text questions were also rewarding and motivating to the pathologist. Higher number of Breast lesions in this study could be attributed to the inherent nature of women to share their emotions with another woman. Similar findings were observed by Booth et al in the consult programme initiated in Lowell General Hospital. They attribute this to the flyer inserted into the breast cancer patient folders.[2] In our study, nothing of that sort was done. Women who had breast lumps came for consultation immediately after collecting the FNAC report as they could not wait till they visited the next outpatient day to see their consultant. Those who had benign diagnosis like cyst or fibro adenoma said they were relieved of the anxiety on a weekend. One patient who had performed USG guided neck node directly without consulting a physician was diagnosed as Tuberculosis by FNAC and gene Xpert from the aspirated material. He was advised to see a physician to take appropriate treatment. Mother who came for consultation said she was worried of it and was relieved to know that it was not cancer. Another patient who was diagnosed as papillary carcinoma thyroid was referred by a homeopathic doctor for FNAC, was advised to consult a surgeon for the required treatment. Questions regarding treatment rarely rose, and if they did, they were asked to consult their treating physician. Discussion was restricted to the role of pathologist in the disease management.

Benefits to the patients or their relatives was clearly visible from the responses. Lepidis et al conducted a study to quantify patient's interest in utilizing pathologist consultation.[9] Majority(75%) of the respondents were definitely interested. Key themes of interest were enhanced understanding of the diagnosis and disease, an opportunity to demystify the diagnostic process, and the perception that additional knowledge would empower the patient. Limitations of the present study were; there was no established patient –consult programme, treating physicians were not informed, no additional notes were documented in patient charts. It was more of an emotional support to alleviate the anxiety of the patients. Three of the breast cancer patients who utilized consultation 15-18 years back have become best family friends, visiting the author(1) on festivals and important family functions. One of them had second breast cancer after a gap of 10 years. Advantages to the pathologist were clearly visible. Sometimes additional information on patient's history enabled pathologist to give an accurate cytologic diagnosis. Increase in diagnostic accuracy by face to face encounter with the patients is mentioned in the literature.[10] The manner in which a pathologist conducts the consultation can a have an impact on the service. Dr Rosenberg advises pathologists to be empathetic towards a patient and be a patient listener, be certain of suggestions and recommendations she or he makes. He also suggests that treating physician has to be in loop or even better to document in the patient's case sheet.[6]

Present study included patients who came to discuss FNAC diagnosis. In a FNA clinic setting patient-Pathologist meeting is brief, mostly limited to consent taking and performance of the procedure. Many

pathologists limit themselves to this and may find uncomfortable to reveal the diagnosis especially when it is cancer. However since preliminary diagnosis is available, Pathologists are in an unique position to provide immediate results that can eliminate anxiety filled periods and expedite the treatment process.[11] Therefore pathologists should not deter to utilize this face- time with the patient. With practice and help of guidelines like SPIKES (setting, perception, invitation, knowledge, empathizing and exploring, and strategy and summary) it is possible to conduct patient consultation effectively.[12]

There are concerns to start as an established service. Other pathologists might feel it an added responsibility and time commitment for no financial gains, some might fear lawsuits and litigations if something goes wrong. Some pathologists simply might choose not to speak to the patient for the fear of causing confusion and contradiction with the advise given by the clinician. Clinical colleagues might feel such consultations can affect treatment protocols or their practice. This confusion and contradiction can be sorted out to certain extent if all three parties meet simultaneously. Work from Booth et al and Smith et al suggests that clinician can be an enthusiastic partner in Pathologist patient consultation.[9] Gibson et al propose a path to set up Pathology explanation clinics (PEC) and a specific category of specially trained laboratory test results-communicators, the so-called "Certified Pathologist Navigators (CPNs). The training would be in such areas as interpersonal communication, cultural sensitivity, clinical medicine, standard and advanced therapeutics, statistics, precision medicine, population health, medical economics, and methodology for assessing patient health literacy.[5]

CONCLUSIONS

Present study clearly reveals the benefits of patient-pathologist consultation. Patients are often unaware of the role Pathologist plays in their care. The medical institutions and clinicians should make patients aware of the expert pathology services available. Pathologists themselves should deem it professional obligation to talk to patients which in turn can make them more visible and professionally efficient. Cytopathologists in particular need to develop communication skills to discuss the disease with the patients. Systematic analysis with a larger sample size and further research can help to identify a subset of patients who will be benefitted by pathologist consultation. Such encounters with the patients definitely bring pathologist closer to the source of tissue on the glass slide.

Table 1: Summary of responses to the questionnaire.

Question	5(strongly agree)	4(agree)	3(neither agree or disagree)	2(disagree)	1(strongly disagree)
1. as the time given enough to address your concerns?.	15(75%)	5(25%)			
2. Was the discussion and explanation of your reports in a language that was easily understandable by you ?	15(75%)	5(25%)			
3. Were you able to understand your disease better after viewing your slides/consultation?	7(35%)	12(60%)	1(5%)		
4. As you have "seen your disease", do you feel empowered and enabled to tackle your disease in a better manner	3(15%)	16(80%)	1(5%)		
5. Would you like to schedule multiple sessions of this programme as a part of your treatment protocol	4(20%)	14(70%)	2(10%)		
6. Would you recommend this programme to someone you know?	12(60%)	7(35%)	1(5%)		

Table 2: Selected responses to free text questions.

Question	Responses
1. What was the most memorable part of this meeting?	1.The way in which slides were explained methodically 2. Reassurance provided 3. Explanation about my disease 4. Relieved of fear of cancer
2. Do you have any additional suggestion/comments to help us improve the patient experience in this process?	1.To have FNA clinic nearer to OPD 2.To have a regular consultation like any other consultant

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