Role of Social Media in Patient Reported Outcomes Research

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INTRODUCTION

- Medical technology allows determination of physical, physiological or biochemical changes in the patient, but it is not able to give all the information about the treatment or disease as some of the data can only be obtained from the patient's experiences.[1]
- Nowadays, the patient's specific experiences during various medical treatments, clinical research and late phase studies are considered as important as physician's and diagnosis reports or clinical findings to make an informed decision.[2]
- A standard measurement tool for directly obtaining the patient's experience on health status is known as Patient Reported Outcomes (PRO).[2]
- The US Food and Drug Administration (USFDA) defines PRO as any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.[1]
- PROs are progressively being recognized as a tool in adding value to the drug review and evaluation process in the developed countries.
- The other types of reported outcomes generally used in the clinical scenario are obtained from clinician, caregiver, and observer.[1]

IMPORTANCE OF PROs

- Patients can express and share the things on healthcare like the opinions, thoughts and complaints that a technology or any other observers can't.[1]
- The symptoms such as a headache, fatigue, cold, breathlessness, pain; psychological symptoms such as depression, anxiety, sleep disturbances; frequency and severity of symptoms; perception or feeling of the patients toward a disease or given treatment can only be expressed by the patients.[1]
- Records such an information on health, quality of life, functional status associated with care or treatment can be more valuable than it seems.
- In some disease treatments, survival is not an ultimate goal but improving the quality of life is of prime importance, e.g., knee replacement and cancer treatment.[3] Thus, PRO is gaining the importance in the clinical world.
- Using PRO the physician can evaluate whether the clinical care is improving the patient's experience or not.[4]
- The PRO also ensures that research under investigation is both robust and valuable for the use of medicinal products, therapy, or health services.[4]

MEASUREMENT OF PRO

- The PRO is measured using an instrument consisting of a questionnaire plus the information and documentation that support its use.[1]
- The PRO measurement instrument or tool can be either general in nature or disease-specific, but the combination of generic and disease-specific PRO measurements are often used in clinical studies.[4]
- The National Institute of Health (NIH) introduced a research design of PRO measurement information systems to develop, validate and standardize the items in questionnaire that are relevant to the common medical conditions.[5]
- The PRO measurements with a wider scope, such as the EuroQol EQ-5D, also analyze the cost-effectiveness of a particular intervention along with the derived benefits in term of years in full health.[4]
- Disease-specific PRO measurements that were designed to identify specific symptoms and their impact on the function of those specific conditions have greater face validity and credibility than general PRO measurements.
- Some of the recent research has recommended the selection of the best measurement instruments. at research under investigation is both robust and valuable for the use of medicinal products, therapy, or health services.[4]

DEVELOPMENT OF PRO RESEARCH[4]

ORIGIN	Initially developed for pharmacological and healthcare service research to improve the clinical care of patients Restricted to England, Sweden, and parts of the US
1975	Nation-wide use of PRO using disease-specific clinical databases known as quality registers This was established in Sweden
2000	PRO as a reimbursement mechanism for accountability within care organization Introduced to some parts of the US
2009	Mandate to use PRO to report outcomes for certain elective surgical patients with National Health Services (NHS) It was applied in UK

- The PRO usage is progressively expanding beyond clinical research exploring its potential to revolutionize healthcare and improve the quality and safety of care for patient-centred decision-making.[4]
- The increased credibility of PRO amongst regulatory bodies who aim to standardize their use and interpretation in clinical trials.
- The growing emphasis on PRO usage and its rationalization has led to the establishment of guidelines on the development, usage, measurement and analysis of PRO.
- The regulatory bodies of the western world have released the guidelines that mandate the use of PRO measurements to support labelling claims.
- The Department of Health, NHS has also released the guidelines on the national standards for routine collection of PRO involving some elective surgical procedures.
- In the US, the government and private insurers are basing the reimbursement on patient satisfaction score.[4]

SOCIAL MEDIA AND PRO RESEARCH

- Establishing and reporting the evidence for medical product evaluation based on social media and newly developed PRO need to be scrutinized for the content validity.[10]
- Although there was a consensus that there is great potential for social media to support content-validity of PRO, identifying an appropriate type of social media remains a challenge.[8]
- The other challenge is to ensure that participants of PRO on social media are representative of the target population while maintaining the advantages of anonymity provided by online platforms.
- Translation of the information and cultural adaptation of the population while implementing PRO worldwide may be challenging.[11]
- There is a scope of future guidance on developing the language-specific methodology or translation methods for specific types of PRO instruments.[11]

CHALLENGES IN USING SOCIAL MEDIA AS A SOURCE FOR PRO

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THE OTHER PRO CHALLENGES

- There is a lack of consistency in the terminologies and methodologies of the PRO measurement while establishing the guidelines.[11]
- The complexity in defining the domain-based items and setting up methodology of PRO measurement for generic or disease-specific health status.[9]
- There is confusion over to what extent any new guidance should be prescriptive or descriptive.[11]

OUR PERSPECTIVE ON PRO RESEARCH

- Healthcare is moving towards a value-based system, where improving the quality of life are benchmarks of good clinical practice. Thus, there is a gradual but real momentum in clinical research to use PROs.
- Companies now certainly need to look into new forms of communication technology to demonstrate the value of products to a wider audience beyond the traditional physician pool.
- As the increase in public demand will continue to upgrade the provider patient experience and patient advocacy interface of social media, effective methods of collecting PROs, there will a need of a more systematic and collective thinking for future consensus.
- The publication of data based on such PROs is likely to find its way onto social media and patient websites, and such information is of interest to both patients and patient-advocacy groups alike.

CONCLUSION

As the social media has a great potential to impacts the patient care in the future through increasing mobile technology usage, it would definitely assist the generation of PRO for a quality and more sensitive healthcare of patients.

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