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Patients' Empowerment in Hereditary Haematological Disorders

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Empowerment is a continuous and multidimensional process. It involves health care providers, patients and families in the adaption of decisions and in taking required action.[1,2] Patients' empowerment ensures a mandate to people in making decisions about their own care ,but very much realistic and under the mentorship of care- givers.[3,4] Accurate understanding and authentic application of empowerment can enable patients to self-manage their disease related issues, which can then lead to improved person-centered care outcomes.[2,5,6]

Patients' organizations often fulfill the task of ensuring education for patients and healthcare professionals by developing and often finding helplines, information and developing training for patients. By this strategy patients can become full-fledged partners in decision making. A proactive approach through goals-setting is an engaging, dynamic and constantly evolving concept. Through it the patient can be versed with different phases, procedures and management options .[5,7,8]

Embracing patients' empowerment requires a paradigm shift, that is often difficult to achieve because of traditional approaches to care, embedded in health care providers' training.[5] Recognition of the importance of patients' voice, in clinical practice, has been steadily increasing. Patients who suffer from chronic conditions frequently experience powerlessness regarding loss of health, identity and from the necessary life changes required for the management of their chronic illness. Patients' journey is a tool that should be read carefully and individualized for each patient, family, treatment facilities available and country, in accordance with new developments. [9] This is especially important in inherited haematological disorders, like thalassaemia and haemophilia. In both these disorders, there is a giant leap. World-over now thalassaemics and haemophilics are seen to hold the reins of their management, up to a greater extent, independently. [5]

The empowerment strategies in thalassaemics witnessed a significant improvement in emotional, physical and social functions. [8] Collaborative efforts revealed improvement in quality of life (Q.O.L) of thalassaemics, regarding psychological and medical issues. Summative and formative assessment in an intervention programme, through SOAPIER format, revealed that after three weeks of implementing the intervention, patients had started to be able to socialize with friends at school, had started hanging out with friends and to arrange a schedule to the hospital, along with his school timing [8-10]

A study by Asa P , et al (2021) shows that empowering thalassaemia patients and their families is an effective method to tackle with day to day problems related with the disease as well as it enables their families to convince other people to know about their thalassaemia status.[11] A study from Indonesia revealed that empowerment yielded a harmonious liaison between the thalassaemics and their families with health care providers.[12] Najafi K et al (2011) reported significantly increased ($p<0.05$) improvement in the group which was empowered, as compared to the non-empowered group .[13]

In haemophilia it is important to give a self-awareness to patients about their disease. They need to accept it and be aware of what it means to live with haemophilia. This process is different for each patient. Education regarding the risks of living with haemophilia and treatment administration is crucial. The care – providers can provide a training programme to administer

treatment at home. During these training sessions the families establish a close relationship with the team, which makes them feel calm and peaceful. There are points which can be applied to all, but there are many aspects which need to be tailored in accordance with living conditions, demographic circumstances and financial constraints .[4]

The patients' engagement and voice need to be assessed in an objective manner. A step towards that is a "Goal Attainment Scaling" (GOAL-Hem). It is a novel, validated patient engagement tool. [7] A concept of "Free Mind Haemophilia" needs to be empowered. This aims to produce in minds of haemophilics absence of physiological burden and of permanent thoughts about haemophilia and its complications. This is paramount to make them a productive component of society.[4, 14] Some tangible and measurable tools ,like conceptual maps, PROMS (a short self-assessment tool),empowerment scales, Patients' Activation Measure, Patient Instrument,betc, are designed and are proved effective. [9,21]

Corto-Rodrignez HD et al (2019) evaluated patients' empowerment in haemophilia and they found that after proper encouragement nearly 70% of patients capable of making decisions on matters affecting their health. Majority confirmed reduction in hospital visits.[1] An Iranian Haemophilia Treatment Center (HTC) studied empowerment in haemophilics, by dividing patients in two groups. One which was made award and trained regarding empowerment and the other which run as a control. Empowerment model encompassed four steps,i.e., understanding threat, problem solving, educational participation and evaluation. Before intervention no significant differences in total score of quality of life (p=0.442) was observed between the two groups. After the intervention a significant difference was observed in terms of quality of life (p=0.03) and family dimensions (p=0.019), friends(p= 0.015), and perceived support (p=0.011) between the two groups.[15]

Patients' empowerment is a move away from paternalistic model. Empowerment is not a simple process, nor is it necessarily linear. It is not a process that can be imposed. It can be facilitated. In the present times patients are well versed with their diseases due to technological access, which is easily available through prevalent media tools. However, the information, which patient accesses independently varies in quality and content. This wealth of information can be powerful, but can be confusing in some extents. [2]

It is important to recognize the role of patients/patients' representatives in hospitals, centers of expertise and other decision- making bodies. It is required to promote patients' training, educational and capacity building initiatives, so as to allow patients to become full-fledged partners in decision making.[16-19]

Fragmented health care system, as of our's, needs capacity building and awareness to understand patients' empowerment. When operationalizing patient empowerment, it may be helpful to consider that relevant actors (patients, health care providers and health care system) may be constrained by some of the moderators identified. For example, the capacity of individual health care provider may be limited by their training, personal values and professional goals. Training interventions to support health care providers to implement shared decision- making may therefore be effective. The capacity of patients to empower themselves may be limited by their personal characteristics, their access to social support and their personal values. Health care providers can consider encouraging patients to identify sources in their social network who could support them to choose personally meaningful ,realistic health-related goals and take steps to achieve those goals. [3, 19,20,22]

"Shared Decision Making" (SDM) can help a lot to people with chronic lifelong aliments, most so in inherited disorders like thalassaemia and haemopilia. Shared decision making is defined as a process in which health care professionals and patients work together to make healthcare decisions using the best available evidence while considering patient' values, preferences and goals. It is emerging as an essential component in thalassaemia and haemophilia care, as both of these involves lifelong treatment and complex therapeutic choices. In this regard patient-centered collaborations between healthcare providers, patients, and families are critical. SDM improves treatment adherence, reduces decisional conflict, enhances patient satisfaction and supports ethical clinical practice. Integrating SDM into routine thalassaemia and haemophila management can ultimately improve clinical outcome and quality of life (QOL).[23-25]

Collaborative patients' empowerment models are likely to improve cost- effectiveness and delivery of care. Empowered patients are likely to be better adopted to

their health conditions, more independent; although this remains to be consistently followed-up and demonstrated.[3] There is a crucial role, in capacity building, of umbrella patients' organizations that act at national level. By pooling patients across the country together and acting as a single voice, national patients' organizations are able to contribute to empowerment at micro(patient), macro(community) and policy level.

The people, with inherited haematological disorders, are walking on the tightrope of life with their crusades on their shoulders, burdened by the ideals that refused to let them rest. They should be encouraged to come forward, to share the responsibility and to hold the reins, until an extent, in their hands. Hats off to the courage, resilience, perseverance of all those, patients and their families and care- givers who are striving to the best of their efforts and skills in this struggle. All credit to those who are actually in the arena and are striving valiantlyl

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