Q.2 Analysis

Extra information from 14/25 responses

SWE (1): Empowerment is a characteristic determined by the patient-caregiver complex either on an individual or on a group level. The patient is confident and able to participate in a dialogue with the caregiver who invite the patient to take part in the diagnostic and treatment processes. It do require some health literacy (patient) and maturity and self confidence (caregiver).

FRA (1): In French Translation it would be : capacity to take decisions and actions for one's own health or to take part in collective decision in relation to health

FRA (2): Patient has and is given the equal choice to decide how she/he gets care, with no monetary penalty

CZK: Assuring, that the "patient" or anyone in need of health services is handled with respect and dignity as a partner in all stages of the healthcare process

SLO (1): Active and responsible participation in his/her health and disease management.

GER (1): Empowerment stands for a process in which those affected take their affairs into their own hands, become aware of their own abilities, develop their own strengths and use social resources. At the same time, it stands for the processes aimed at developing individual competencies. According to the concept, which is based on a humanistic view of human beings, the strengthening of competence and self-confidence starts with the efforts that individuals make anyway in order to develop and grow. I see three central principles of empowerment: autonomy, distributive justice and participation.

GER (3): There might be very sophisticated definitions out there. To me the most important part is the aspect of democratized healthcare which also transfers to the definition and role of the citizen and his / her fundamental rights. With the pandemic measures that governments take in a more or less paternalistic way this was most likely not positive for the overall case of patient empowerment.

IRL: Enabling collaboration between patients/service users/families and carers and health care professionals at individual, organisational/governance and policy making level.

UK (1): The activities, capabilities and opportunities that enable a person/persons to make a informed choice, based on what matters to them in regards of how they would like their health care provided and the treatments, including doing nothing that they would like.

Or, an empowered patient is: a person who has the capabilities, opportunities, confidence and motivation to make informed choices about their health and wellbeing and any care needed to enable those choices based on what is important to them

UK (2): A Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well, and are seen as equal partners in their care

ESP(2): I like the definition provided by ENOPE (http://www.enope.eu/patient-empowerment.aspx):

“Patient empowerment puts the patient in the heart of services. It is about designing and delivering health and social care services in a way, which is inclusive and enables citizens to take control of their health care needs.”

I also agree with the definition provided in the paper “A new understanding of health related empowerment in the context of an active and healthy ageing. L Kayser, A Karnoe, E Duminski, D Somekh, C Vera-Muñoz. BMC Health Services Research 19 (1), 242”.

((1) Empowered individuals are able to and motivated for taking action(s) in daily life to the extent that they wish to do so, to improve their health and well-being.

(2) A necessary prerequisite is that they are health literate, i.e. have the knowledge and competencies to manage their health and well-being,

(3) they are self-aware and can choose to be involved in the co-management of their health,

(4) and able to adjust their health-related behavior if meaningful for them.

(5) Health-related empowerment interventions aim to equip individuals and their caregivers whenever appropriate with the capacity to collaborate in decisions related to the condition to the extent that they wish and are able ***to do so;***

(6) to enable co-management of the condition; through mutual agreement between the individuals and their formal and informal caregivers;

(7) and to develop the individual’s confidence and coping skills,

(8) enabling them to manage the physical, emotional and social impacts of their condition that affects their everyday life.

(9) Empowering interventions foster the development of health literacy among staff and the people that they serve

NL (1): For me, it's about every person being able to live his or her life as it suits him or her. That every person is of significance for himself and for society. That every person can take responsibility for his own life (the extent to which differs from person to person). And that, while recognizing everyone's vulnerability as a society, we look together with people to see what they need and find important. In essence, it is about being a fully-fledged and valuable person at all times and not being reduced to your illness, condition or deficiency. It also means that where care and/or support is needed, it happens with people and not over their heads. Every person is sovereign.

NL (2): I would define Patient Empowerment as the process of enabling patients to take responsibility for their own health.

NL (3): In my opinion the empowerment of people should start before they become a patient. Awareness of influence on and responsibility for your own health and well-being should help. Knowledge of factors that have a positive influence or negative influence on that, should be widely available and spread by education, public campaigns, public dialogs. The power of (small) social related and local communities can be used by that.

When some-one becomes a (chronical) patient he or she should be supported in finding nearby peers. Together they can let themselves inform by different kind of professionals (education) and share practical information about experiences and self-management with their specific problem or disease. Also, the social system of the patient should be encouraged to participate in this peer-system.

Patient empowerment is in my opinion the support to people to stay (or become) the owner and influencer of his/her health and well-being in the context of his/her social context (home/work/relations etc.) by learning from professionals and peers about do’s and don’ts, and practical solutions.

Commentary: does the material from Q 1 and 2 change our perspective on patient empowerment as a transferable concept?

Certainly, it seems that the majority of respondents from the 14 countries only use aspects of the concept as defined in 2014 by the EMPATHiE or subsequently in the Kayser et al paper of 2019. If there is such a disparate use of terminology (see ‘Aggregated summary of terms document) is it meaningful to refer to ‘empowerment’ as a definition of anything? Is there a better term to use for an umbrella concept?

Initial thoughts are that we need to spend a little time thinking this through and then go to the Expert group with some targeted questions for them to address (assuming they’ll have limited scope for processing the data).