

The “Patient’s Empowerment rights-duty Charter”: new communication tools targeted at patient and professionals in a Hematology and Bone marrow transplant center

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Summary. *Background and aim of the work:* Empowerment is very important to keep high staff motivation and attention on patient safety. The aim of this study was to produce a “Charter of Rights-Duties for Patients’ Empowerment”, by developing empowerment both of patients and professionals of the Hematology and Bone marrow transplant center Unit of Parma University Hospital. *Methods:* The professionals were actively involved in meetings to complete the Italian version of the SESM Empowerment Questionnaire, draft the Charter and produce some communication tools to be implemented in the Unit. *Results:* All professionals had participated to the research. The level of empowerment in the unit, both for doctors and non-medical staff, is very high. This result, the Charter and the others communication tools are now known and shared by all. *Conclusions:* Stimulating empowerment seems to be a winning choice. It is important to involve professionals right away in the process because a high level of staff empowerment can generate a good field for high degree of patients’ empowerment, that can increase patient safety and reduce the risk of dangerous health choices. This approach aims to increase patient safety through the collaboration of patients, volunteer associations and professionals. Communication programs must include the development of empowerment: it motivates citizens to engage and the literacy enables them to make informed and reasoned choices. General Management is now evaluating how to realize the program in each ward, discussing the importance of carefully conceptualizing this approach for the design of health interventions. (www.actabiomedica.it)

Key words: patient empowerment, professionals’ empowerment, clinical risk management, patient safety and prevention, hematology, bone marrow transplant center

Introduction

As the WHO has repeatedly called, the citizen must be the first actor of the choices that affect his health and, because this is achieved, the active participation of citizens in the socio-sanitary processes involving them must be promoted, using a “shared” approach to the decision/management of pathways and

health care: since 1994, WHO has defined the Principles of Patients’ Rights in Europe (1) and in 2007 it underlined the primary importance of People at the Centre of Health Care (2). Many studies, scientific works and international reports, say that the National Health System need a more patient centered approach (3) and support that the way to drive change is working together for excellence, creating a continuously im-

proving consumer engagement framework for excellence in patient-centered care (4).

In Italy, the AgeNaS (the Italian national agency for regional health services) since 2007 has established an Interregional Empowerment Working Group, precisely to promote the development of individual, organizational and community empowerment processes. The importance of citizens' empowerment for the development of Health Care System is underline in many AgeNaS publications, which summarize the national experiences in this area (5) and underline the citizens' experience in improving regional and national health services (6). The Empowerment Working Group, which deals with empowerment of both patients and professionals, has adopted the following definition of empowerment: "(...) is a process of social action through which people, organizations and communities acquire competence over their own years, in order to change their social and political environment to improve equity and quality of life" (7).

The concept of empowerment, which has for some time now been part of the common language of those who care for health and care, translates, on the one hand, to the professional awareness, engagement and empowerment, and on the other side in the growing capacity and awareness of the citizen in taking care of himself. The citizen is empowered when acquiring knowledge, skills, attitudes and awareness to influence one's own and other behaviors, to improve the quality of their own life and their "well-being" even in critical conditions.

Schulz and Nakamoto, in a 2013 article on Patient Education and Counseling (8), insist on the importance of distinguishing mastery/mastery and health literacy/literacy: both are needed, and in cases where there is one without the other, problems arise. In summary, the single actor, whatever its role (citizen or professional), once empowered, becomes part of a system that involves and enhances that attitude, to be transferred to interpersonal relationships and care paths, and, more reason, to be the basis of the health-care organization that delivers them.

When the healthcare provider first engages in patient and citizen empowerment programs, he needs to be supported in his professional empowerment path. First of all, it is to stimulate a cultural change, leaving

behind the traditional way of understanding the profession to look at things with other eyes.

This research has stimulated professionals of the Hematology and Bone marrow transplant center Unit from University Hospital of Parma to actively engage the patient in the cure process by creating a new patient communication tool. The "Patient's Empowerment rights-duty Charter", which is the principal result of this work, has been written by professionals to make precise commitments to the patient and to feel part of the process of empowerment both of themselves and of patients, in a growth, personal and professional development, aimed at increasing the quality and safety of care.

Materials and methods

The project, supported by the "Chiara Tassoni Volunteer Association" of Parma (it is a volunteer association for the research into leukemia and cancer), started with a first phase of bibliographic research, which lasted from June 2016 to August 2016, with a view to compiling the studies already carried out on the empowerment of patients and professionals - and to find out which tools and methods - particularly in the field of oncology and hematology.

The second phase of sharing with Hematology and Bone marrow transplant center Unit from University Hospital of Parma, Italy, took place in September-November 2016, with the first planning and sharing meetings involving the Director of the Structure, the Nursing Officer and some professionals. The purpose of these preliminary meetings was to share design lines with the project headquarters structure, so as to lay the foundations for intervention based on involvement and active participation of staff.

The third stage of selection of survey tools was completed in November 2016.

The fourth phase of activities started and the implementation of the design phases began in December 2016 and lasted until March 2017.

The fifth and final phase of returning results and dissemination and implementation within the structure of communication tools implemented with the project was completed in May 2017.

With regard to future developments, the tools implemented with the project will be in use from June 2017 onwards in the Hematology and Bone marrow transplant center Unit and will evaluate the applicability and dissemination (with appropriate modifications) at the best practice level also in other departments and business structures, in order to optimize the resources used in the project and put the tools at the disposal of the largest number of professionals and patients.

The survey sample is made up of all the staff of the Hematology and Bone marrow transplant center Unit which respected the requirement of "work in the ward/outpatient clinic, mainly in contact with the patient". Samples were then excluded according to the following criteria: "poor interaction with the department", "membership of the stem laboratory", "transfer to another health company in progress", "secretarial duties only", "pregnancy".

For the data collection and the gathering of the opinions of the professionals, 6 meetings were held at the facility: making directly at the facility wanted to facilitate access to the initiative and give everyone the opportunity to participate, compatible with the shifts of the individuals and service needs.

Each meeting has got three distinct phases:

- Presentation of the goals of the project and tools that we're going to build;
- Discussion by Focus Group on the "Empowerment Citizens' Rights Charter";
- Compiling the "Empowerment Questionnaire".

Based on this kind of participative method, fundamental to the success of the project was the collaborative role played by the department's medical and nursing staff who promoted the initiative, actively supporting the Clinical Government Unit, for collect membership and equal distribution of operators inside the various editions of the meeting. During the meetings, the choice of the focus group methodology allowed us to look at the opinions and to gather concrete proposals from all the participants who participated (43 operators on the 6 editions), which they felt called contributing and expressing themselves first, as well as being directly involved and valued. We have made it possible to complete the empowerment questionnaire also to other 3 operators who could not participate in the meetings, so as to have everyone's answer.

The "Patient's Empowerment rights-duty Charter"

The focus group discussion forum was the "Patient Empowerment Patient Charter", prepared by the EPF (European Patients Forum) for their campaign to promote the empowerment of the patients in many European hospitals over the years (13). The Charter consists of 10 items, each briefly described and supported by the authors, which touch upon all the many aspects of the citizen's relationship with the public institution on health and safety of care in terms of the demands and rights that every citizen should/It would also like to have, at the level of law, the ability to play an active role in the decisions concerning its state of health and the process of care. Being born only from the bottom, the citizens and their representatives, the Charter in its original version presupposes a very high commitment from professionals to meet the demands and ensure the real application of the content and principles contained therein. The project did not want to assume that professionals felt able to take on such a commitment in all the points outlined in the Charter and wanted to explore the real possibilities of implementing the tool, giving the professionals the opportunity to Customize the Charter to their department and for Hematology and Bone marrow transplant center Unit. For this reason, the focus group aimed at examining in detail, together with the operators, every item of paper and evaluating the real possibilities of application within the daily activity with patients, both in terms of content expressed and, above all, based on the level of empowerment perceived in turn by the operators in relation to the structure and, more generally, of the national health system. During the meeting, after the introductory phase of project submission and data collection tools, it was to read, discuss and reformulate with each operator each item of the paper in its original version, to build a specific paper, totally Belonging to the department and filtered through daily experience.

The "Empowerment Questionnaire"

Another goal of the meetings was to strengthen the internal climate and the relationships among professionals, encouraging the exchange of views and directing the forces of everyone towards the creation of a

single instrument (the Charter), shared at the medical and nursing level, to be distributed to users, as a “basic document” for mutual engagement between the users and the multiprofessional team. In addition to arriving at the drafting of the Charter, it was in the intentions of the project to experiment with the use of a questionnaire that would reveal the level of empowerment first in the professionals, then (eventually) in the patients. In this logic, through the administration of the questionnaire to professionals, they wanted to give them a chance to reflect on the possible use of this tool with patients, starting with the emotions and reactions they themselves experienced in compiling. For this reason, the questionnaire chosen is the SESM - Italian version of the Scale of Users to Measure Empowerment in Mental Health Services (14), as it was considered that this instrument affected the main dimensions involved in demonstrating the difficulties of these types of patients and which would, however, allow to monitor the main variables involved in the process of empowerment at the individual level, regarding actually working conditions and ways of seeing life and making decisions. The questionnaire was anonymous, but at the time of compilation, operators were given the opportunity to enter their name and address if they were interested to receive privately their personal result.

Results

All the professionals have decided to take part in the study (N=46), so the results do not refer to a sample, but to the entire population of professionals operating in Hematology and Bone marrow transplant center Unit and the 67.39% of the operators signed the questionnaire also if anonymity was allowed. 41.3% were Doctors and 58.7% were non-medical personnel (nurses, assistant nurses and biotechnology laboratory technicians). About gender, 23.9% and 76.1% were male and female respectively. Regarding the age of the participants, the distribution was the following: 2.2% is <25 years; 47.8% is 26-35; 17.4% is 36-45, 28.3% is 46-55 and 4.3% is >56 years. Regarding the total working seniority in healthcare, the distribution is 4.3% was <1 year; 69.6% was 1-20; 17.4% was 21-30 and 8.7% >30 years. About the experience in an Hematology

Unit, the result was as follows: 17,4% is <1 year, 76,1% is 1-20, 2,2% is 21-30 and 4,3% is >30 years.

The survey results are reported in terms of:

- a) Final version of the “Patient’s Empowerment rights-duty Charter” in Hematology Unit;
- b) Evaluation of the general level of professionals’ empowerment and analysis of the individual aspects of the multi-professional team’s work (working conditions and decision-making).

The “Patient’s Empowerment rights-duty Charter” in Hematology Unit

The result of this part of the project is the editing and spreading of the Charter in Hematology and Bone marrow transplant center Unit, that is the outcome of the meetings with the operators and the subsequent revision and final approval carried out during the meeting with the Director of the Unit, the Nursing Officer, some professionals and the Volunteer Association promoting the project. The final version of the Charter (produced also as an information brochure and as posters to be posted on the walls in the department) is currently being tested at the Hematology and Bone marrow transplant center Unit and will be approved by the hospital’s management at the end of the year. Next, the Charter will be published on the company’s website for free use by those interested in using it in their Hospital Units.

The results of the empowerment questionnaire (SESM - Italian version)

Totally 46 questionnaires were collected, so all the operators of the Unit expressed their opinion. The information contained in the questionnaires was placed in a Microsoft Excel spreadsheet and subsequently treated statistically (Correlation analysis between groups; Scale analysis). The questionnaire contains 28 items, which provide the answer following the following Likert scale: 1=fully agree; 2=agree; 3=disagree; 4=absolutely disagree. The test author defines a low level of empowerment when you get a total score of 28 points and a high empowerment level when you get a final score of 112 points and therefore sets the cut-off (mean central empowerment value) on 70 points.

Only one value on the 46 questionnaire falls below 70 points. The overall result of the sample gives a middle-high/high empowerment level of all operators and, as can be seen from the diagram, the values are equally distributed between doctors and non-medical personnel (Empowerment Means Value: Doctors, 84.15; Non-Medical personnel, 82.15). The diagram below shows the empowerment values obtained by the operators (Figure 1).

About the Correlation analysis between groups, the gender variable did not appear to be significantly associated with empowerment scores (U of Mann-Whitney=171.5, p=.587) and the same thing was repeated with regard to professional qualification: in fact, the two subgroups of doctors/non-medical personnel do not show significant differences in their empowerment scores (U of Mann-Whitney=218, p=.389). Spearman's non-parametric correlation analysis showed that the participants' empowerment scores do not vary with age (Rho=-.217), professional seniority (Rho=-.183) and work at UO of the participants (Rho=-.046) significantly.

About the Scale analysis, in the validation of Rogers et al. were identified 5 underlying factors (self-esteem/self-efficacy, power/impotence, community activism and autonomy, optimism and control in the future, justified rage); in the present study the Direct Oblimin Rotation of Main Components (ACPs) revealed 9 components (with values above 1) that reached convergence with 14 iterations and account

for 71.6% of total variance. The total empowerment scale is therefore not supported by the ACP, showing a low internal insufficiency score ($\alpha=.592$). It would be interest in the future to set up a study with a larger number of participants, in order to have a large enough sample to be subjected to such statistical analysis and see if certain factors become significant.

Even if it is not provided by the original tool, a detailed analysis of the responses given to the individual items of the scale was also conducted. The mean values (Likert scale: 1=fully agree; 2=agree; 3=disagree; 4=absolutely disagree) are good for almost all aspects investigated, particularly for item 3 "people have more power if they join in groups" (1,5), item 11 "working together can benefit your community" (1,5), item 16 "usually I just feel alone" (3,0), item 28 "working with others in my community can help improve things" (1,4). There are, however, some possible improvements, in particular related to item 2 "I just keep doing things that I'm sure to do" (2,8), item 4 "getting angry at something needs nothing at all" (2,4), item 7 "I should be more capable of saying what I do not like about the behavior of others" (2,1), item 14 "when I make projects I'm almost certain to realize them" (2,3), item 17 "experts are in the best position to decide what people should do or learn" (2,5), item 18 "I am capable of doing things as well as most other people" (2,2) and item 21 "you cannot fight against the power of the institutions" (2,9). The graphic below shows the means obtained from each item (Figure 2).

								N-M		N-M								
								N-M		N-M								
					N-M			N-M		N-M	N-M						N-M	
			N-M		D			D		N-M	N-M	N-M	N-M				D	
			N-M		D	N-M	D			D	N-M	N-M	N-M	N-M		D	N-M	
N-M	N-M	N-M	D	N-M	D	D	D	N-M	D	D	D	D	D	D	D	D	N-M	D
69	72	75	77	78	79	80	81	82	83	84	85	86	88	89	90	91	94	

Figure 1. Empowerment values obtained by the operators of the Hematology Unit (N=46), pointing to the green color of Doctors (D) and in blue color the Non-medical personnel (N-M)

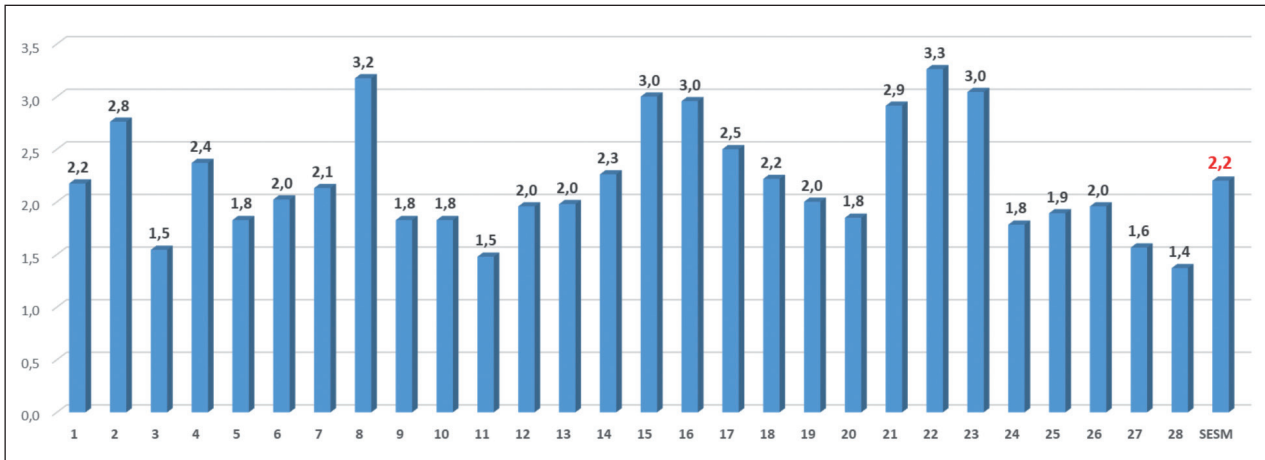


Figure 2. Mean values obtained by each item of the SESM empowerment questionnaire

Discussion

Data from the questionnaires are presented here in aggregate and anonymous form, but we have the 67.39% of the operators decided to sign the questionnaire: this figure, in addition to the maximum level of participation in the survey (which has reached 100%) is, in our view, a very encouraging sign for the continuation of the initiative, a participant of interest and adhesion convinced to the project by the professionals, who were obviously enthusiastic and felt involved in the topic being dealt with.

About the Scale analysis, we have not the same that there is in the validation of Rogers et al., but our research involved by virtue of things a few operators (all the staff present in the nematology unit), so it would be interest in the future to set up a study with a larger number of participants by a greater number of wards, in order to have a large enough sample to be subjected to such statistical analysis and see if certain factors become significant.

Even if it is not provided by the original tool, the detailed analysis of the responses given to the individual items of the scale and the means values obtained, appear as a resource that supports the staff and the individual during his professional activity: in that way professionals will be stimulated to improve these aspects to foster the development of life skills and continue in the process of empowerment undertaken with the project.

Conclusions

Many studies indicate that people with malignant hematomas (leukemia, lymphoma, and myeloma) tend to have less psychological control (9). Compared with what happens in solid tumors, there is a significantly lower percentage of patients who want to participate in clinical choices in hematologic cancer, and there are many more who want to have a passive role. Poor psychological mastery combines poor social mastery, and one favors the other. For a number of reasons, therefore, in the hematological field there is little propensity to empower the patient. For example, Ernst J. et al. in their studies seem to conclude that the desire to remain passive for hematologic patients must be respected without attempting anything to not force them (10). But to look at this, this way of thinking, at first very respectful of people, denies that a hematologic patient, made more capable of handling fear and approaching scientific knowledge and placed in a different clinical context, can modify your preferences and experience of the disease more prominently, working with the professional during the course of care. Sadak K.T. et al. presents innovative educational approaches to engage and empower the adolescent and young adult childhood cancer survivor, and they confirm that patients' empowerment is possible and recommended also with this kind of patients (11). Also Dubrovsky A.S. et al. underline that innovation in patient engagement and empowerment has been identified as a priority area,

and with the "We Should Talk" campaign at an academic pediatric hospital, by the use of a guiding theoretical framework and a multidisciplinary project team, they realize a multimedia campaign with a lot of new communication tools, specially designed to inspire at the same time staff, patients and families to effectively communicate to improve patient safety (12). The "We Should Talk" campaign provides a case study for how an organization can foster frontline improvement through the engagement of patient, families, staff and healthcare providers.

To achieve these goals is indispensable and fundamental that the patients and the citizens' commitment to patient empowerment be based on the abandonment of traditional paternalism that puts the patient into a state of passivity and relegated it to the role of a mere "recipient of benefits". Professionals need to develop the skills useful to create and maintain a dynamic and interpersonal relationship with the patient, providing valuable information and clinical indications about their health status, must continually access scientific literature and acquire knowledge based on the needs of the moment, and transfer knowledge to the practice. It is challenging to feel good operators, sure of themselves even in fluid situations, dynamic interaction, often dependent on others and the tools the world offers. In some cases, they are reconfiguring their professional identity, moving from the professional paradigm of "personal skills possession" (according to which "I am a good professional because I possess the necessary skills"), which impels to rely only on oneself in a state of isolation, to that of the "dynamic distribution of skills" ("I am a good professional because I have to do it continuously to have the skills they need when they serve, even by comparing and acquiring external aid").

The empowerment in literature is proposed under two different but increasingly integrated perspectives: as a tool and as a goal. In this study we used both approaches together: as an instrument, to obtain in the community the desired changes, and as a goal of intervention, to build and mobilize, through participated processes, the internal and external resources that are necessary to be able to put in place autonomous and responsible choices. The novelty of our approach is that there is no study in literature that had taken charge at the same time the empowerment of professionals and

patients and it is also the first time that the Italian version of the SESM Empowerment Questionnaire (14) was used with professionals: with this survey we want to lay the foundations for a deepening in this regard.

The project, in addition to producing the Charter as a tool for communication to the users and a measurement of empowerment among the staff, allowed to discuss and reform together with the operators every aspect of their professional activity, stimulating their sense of belonging to the Hematology and Bone marrow transplant center Unit and increasing the level of participation and involvement in increasing the quality and safety of care.

The added value of this research lies also in improving indoor climate and close partnership between Clinical Governance Unit and wards, with a view to working towards excellence and improving service for the users. The great interest of the company's general management and the strong sponsorship of the project are other elements that will hope for a continuation of the initiative and for the widespread dissemination of this kind of work to all the other hospital Units. Investing in the process of empowerment of professionals and users, acting simultaneously on the two sides, has been a success factor in this work and has resolved and involved those who, when in contact with the users, send more to everyone's commitment to quality and safety of the hospital care. They now have an idea of the meaning and importance of empowerment, they have more consciousness and also an instrument to measure it with patients (that they are able to administer and process statistically by themselves).

Another goal of the project is certainly the consolidation of the great collaboration with volunteering associations in this area: the Charter obtained at the end of the meetings, which describes the citizen's rights and duties as well as the most closely related aspects of empowerment, is in fact the result of the commitment of all the operators of the ward, who are the authors and owners of the instrument, which we hope can become a useful and effective communication tool for the users, a support for daily work, shared and familiar to all the operators, precisely because they are born from them, with a view to preventing internal conflict (between operators) and external (with the users and their family/caregivers). The support of the

volunteer association, which has been involved since the design of the study, is a central point of contact between the professionals and the needs of the citizen. The empowerment of the citizen is possible if the professionals feel empowered and believe they can affect the relationship with the patients who so become allied to the care process in a total quality of care, characterized by equity, appropriateness and security of the received treatments.

Currently in the Unit, there are in use the communication tools of the project, the Chart, the empowerment questionnaire and another questionnaire to verify the principles of the Charter, that is administered to all patients at the end of the hospitalization/access to the surgery: we hope that this new survey and collecting data will give confirmation in the same direction and that soon, once assessed the outcomes on the nematology unit, we can extend the study to all hospital wards.

Acknowledgments

The authors would like to thank “Chiara Tassoni Onlus-Volunteer Association for the research into leukemia and cancer”, Parma, Italy for its contributions.

Conflict of interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article

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Received: 19 October 2017

Accepted: 20 July 2018

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