

Narrative Based Medicine as a tool for needs assessment of patients undergoing hematopoietic stem cell transplantation

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Abstract. *Background and aim:* In the last years we have seen an ever increasing number of patients with haematologic disorders who need hematopoietic stem cell transplantation (HSCT). The whole sector of HSCT results, in fact, to be in a continuous scientific and technological clinical progress, offering a very advanced care. Despite this, some aspects are underconsidered, some of which could be fundamental to determine the success of the care pathway, such as the experience of the illness by the patient. Using a Narrative Based Medicine approach we wanted to investigate clinical, psychosocial and organizational aspects of the patient's journey whilst undergoing HSCT. *Method:* Various narrative interviews were conducted using non-structured approach. Results were analysed by thematic contents. *Results:* Psychological dimension is the most compromised: above all emerged sentiments of oppression linked to the isolation period in the Low Bacterial Load (LBL) room. To note are also the different dynamics with which the patients perceive the organisation and hospital structures, and how much these factors can influence their care experience. *Conclusions:* Results suggest the need in clinical practice of an integration between qualitative and clinical approach, so as to permit the psychosocial and relational necessities to emerge, often unexpressed by patients undergoing HSCT.

Key words: Narrative Based Medicine, clinical practice, life experience, qualitative research, hematopoietic stem cell transplantation, organization, psychology, nursing

Background

In clinical practice, patient narratives are considered to play a key role in making diagnostic assumptions and developing care pathways. Nevertheless, in the last few years new technologies have led to a growing gap between healthcare staff and patients, as tests and instrumental investigations have often replaced information from patients' narratives (1). Narrative Based Medicine (NBM), a model developed by Dr. Rita Charon in 2000 (2), went the opposite way. In recent years, this model has been strongly supported, as it is very useful in understanding the story and real life of many types

of patients such as cancer patients (3), Acute Coronary Syndrome (ACS) patients or other chronic diseases. NBM can even impact on outcomes, such as improved therapeutic compliance (4, 5) and better health care (6).

At the same time, an increased number of patients affected by hematopoietic disorders (both oncological and non-oncological) underwent both autologous and allogenic HSCT (7) was observed. Such treatment involves a conditioning regimen based on chemotherapy and/or radiation therapy, in order to eradicate underlying disease, make room for the transplanted stem cells and create immunosuppressed recipients, so as to prevent graft versus host disease (GvHD) (8).

HSCT includes a series of adverse events and collateral consequences with short, medium and long term effects, related to drug toxicity and allo-reactivity of transplanted cells (9). Immunosuppression and severe pancytopenia related to conditioning regimen leads to an extended period of isolation in rooms with Low Bacterial Load (LBL) with positive pressure, frequent air changes and air filtration of microbial particles (10), in order to reduce the high risk of infection (11). Patients in protective isolation may suffer with loneliness, lack of freedom and psychological distress (12, 13). These feelings are caused by the sensation of imprisonment (14). Along with prolonged hospital stays during HSCT, these patients need a long period of follow up as outpatients due to post transplant complications. Italy is considered to be at the forefront in setting up clinical care pathways, with more than 100 national Transplant Centers.

Nevertheless, Italian researchers have published few qualitative studies on the psychological, social and relational issues related to HSCT patients.

“Narrative medicine specific guidelines in clinical-care settings” defined NBM as an interventional, relational and pedagogic model able to highlight unexpressed needs, digging deep into personal life experience (15). Due to the fact that NBM considers the disease as an event with different perspectives and meanings, it would seem particularly capable of assessing HSCT patients’ experience, leading to effective and shared care pathways integrating scientific and narrative medicine (16).

Aim

Study’s aim was to investigate psychological, relational, organizational and clinical care issues related to HSCT patients in an NBM perspective.

Materials and methods

Unstructured interviews were planned so as to include questions to improve patient’s ease (“How are you?”, “When did you receive HSCT?”, “Do you like this room?”); a supportive question (“Tell me some-

thing about your experience”) and a final question (“Would you like to tell me something else?”). This method foresaw that the patients were never interrupted, permitting them to speak freely about whatever they consider important and relevant regarding this experience (2). Interviewer noted also pauses, sighs, emotional moments, changes in speaking tone.

Participants

Participants were recruited by a proactive method. Thirteen ≥ 18 year old patients had a post-transplantation follow-up at the Day Hospital of a University Hospital in Naples. All patients had received transplantation in the previous 5 years (nine patients at HSCT Unit in the same hospital, four patients at HSCT Unit in a different Italian Region). Regarding participants’ demographics and clinical features, average age turned out to be 37 years, 38.4% (5/13) female patients and 61.6% (8/13) male patients. Average timing from transplantation was 15 months.

Setting

After having received hospital authorities’ consent, interviews were carried out from July to September 2015, during programmed appointments, in a dedicated room outside Day-Hospital area. Trained interviewers met patients in a *welcoming attitude*, respecting their privacy and avoiding any kind of distraction. Interviews lasted on average 18.37 minutes each; relatives or healthcare staff were not allowed. All interviewed patients had previously given their written consent for participation in the trial, audio-recording and personal data processing.

Data analysis

We did Verbatim transcriptions of interviews noting pauses, sighs, emotional moments, changes in speaking tone. Each transcription was followed by a two-step analysis. First, we examined interview content, thanks to a careful transcription reading: we split each narrative unit into simpler periods and then divided it according to categories (A, B, C, D, E) and sub-categories, with reference to organizational,

clinical-care and psycho-social-relational items. Subsequently, we measured each sub-category within its respective narrative (17, 18) and made an overall assessment, thanks to triangulation of data (19). Only when investigators had unanimously agreed on categories and sub-categories, were data included.

At a second level, we counted the most frequently used words, employing Word Counter software on OsX platform.

Results

In compliance with literature, our research showed that NBM is able to thoroughly analyze both clinical or healthcare details and psychological, social and relational topics (20) related to HSCT patients.

Results have illustrated the significance given to the Patients' experience of the disease. These results underlined the different dimensions investigated during the several steps of the care pathway. The analysis of the most frequently used words (table 3) showed that all patients focused their attention on the time of transplantation and the immediately subsequent period. In fact, the most frequent word was "transplantation".

Table 2. Categories and sub-categories frequencies (Tot. 814)

A	A1	A2	A3				A (all)
	42	58	48				148
B	B1	B2	B3	B4			B (all)
	82	13	14	26			135
C	C1	C2	C3	C4	C5	C6	C (all)
	51	33	39	31	32	64	250
D	D1	D2	D3	D4	D5		D (all)
	17	42	41	16	15		131
E	E1	E2	E3	E4			E (all)
	16	84	49	1			150

Table 3. Words more repeated by the participants (frequencies and N° of subjects)

Words	Frequency	N° of subjects
Tranplant	138	13/13
Good	114	13/13
Day/s	103	8/13
Person/s	107	10/13
Before	92	12/13
Doctor/s	77	11/13
Sterile room	59	12/13
Home	59	10/13
Disease	53	11/13

Table 1. Categories and sub-categories by the narratives

A: Organization	A1: Before HSCT	A2: During HSCT	A3: After HSCT			
B: clinical and nursing aspects	B1: signs and symptoms	B2: alimentary problems	B3: other problems	B4: diagnosis and treatment intervention		
C: psychological aspects	C1: LBL staying	C2: chemotherapy effects	C3: post-HSCT problems	C4: religion	C5: future expectations	C6: psychological general methods
D: social aspects	D1: donor relationship	D2: familiar issues	D3: social relationships	D4: work issues	D5: burocracy issues	
E: relationship aspects	E1: diagnostic interview	E2: relationship with doctors	E3: relationship with nurses	E4: relationship with other patients		

Psychological issues

Psychological issues turned out to be the most frequently discussed ones (250/814). Most interviewed patients (10/13) considered transplantation and cancer related issues as more relevant in comparison to other problems (64/250). Feeling oppressed during hospitalization in LBL room ranked second (51/250) with some patients reporting their hospital stay experience like being in a prison cell.

"I understand now what prisoners feel, it's like living in a prison....Except that the prisoner is comforted by the fact that he is healthy ...I mean ... we don't even have that relief; because anyway, physically we feel, as I say, like squashed flies..."

Another significant stressful moment from the psychological point of view declared by the patients was the Hematopoietic Stem Cells (HSC) infusion. They called it their "Rebirth".

"After I received stem cell infusion from my sister's bag(stem cell bag),the values started to increase and I felt like I was reborn..."

"... There is this huge bag, to tell the truth it resembles a blood bag. You know it gives you back your life, each drop is a vital drop, helping you to be reborn....."

Relational issues

Interaction-communication with healthcare staff (physicians and nurses 150/814) was the second most frequently mentioned category. Physicians and nurses were considered paramount in HSCT patients' care pathway. Relationship with physicians was the topic patients most frequently mentioned(84/150), although with different meanings.

"The physician I was lucky enough to meet is a very good doctor. I.. I sincerely thank him as he showed me empathy. Never I am the physician, you are the patient..."

Other patients reported physicians treated them just like "numbers".

We were treated like numbers like sick patients, rather than people. Do you have a serious disease? Take this, this and this. Are you well? Ok, I'll see you in three months ..."

Regarding healthcare professionals roles and attitudes, patients drew a clear distinction between physicians, who make diagnoses and treat diseases, and the nurses who take care of patients go beyond the technical duties associated to their institutional role, especially in the isolation room.

"Physicians treat you and take care of saving your life, they prescribe drugs, convince you to be transplanted, they teach you how to take care of your own body. Whereas, it's the nurse who really supports you, being at your side 24 hours a day, really all day long, he even holds the bucket when you are puking.... And this is what really matters when you are in the sterile room ..."

"Nurses are really important, they help you do everything, they know how to handle you, they pay attention to you, they understand your nature, your attitude, your way of thinking and they talk to you. These attitudes have paramount importance for patients"

"Nurses kept us company and took real care of us. When I entered hospital, there were 5 male nurses and I had no problem whatsoever... They were like angels to me! Whenever I needed help, they helped me..."

Organizational issues

Our study allowed us to obtain information, above all how hospital organization determines the way patients experience disease pathway (148/814).

Organizational and structural issues turned out to be the most commonly underlined ones in the peri-transplant period. Some patients evaluated by extra-regional centers, reported they had not received information about the possibility of having HSCT in a center located near home.

"I didn't know! I have just learned that transplantation could be done here. [...] I only found out about it when I had my checkup, last month [...] for goodness' sake ...it's an excellent centre for bone marrow transplants. But if I

had known I could undergo transplantation not far from home, I would have considered it ...”.

From organizational point of view, HSCT patients who received treatment out of their region were critical regarding HSCT follow-up at Day Hospital in Naples. In particular they complained about the numerous patients also with different levels of disease gravity visited on the same day and in rooms that were too small and inappropriate, which are unfit for their immunodeficiency condition.

“The waiting room is an enclosed balcony with chairs allocated for patients who have just undergone a transplantation and – in my opinion – they should be in a separate waiting room, more adapt to their conditions...”.

Patients in fact recognize that healthcare staff, even though well trained and competent, work in facilities which don't conform to minimum structural requirements. Moreover, they think the number of staff members is not enough, in particular if compared to other healthcare facilities. They criticize the lack of rooms for follow-ups, in addition to complaining that patients with so different HSCT timing are visited contemporarily, causing those who received transplant a long time before to relive unpleasant memories.

Moreover, patients consider the decision to fix too many follow-ups on the same day is inappropriate, because they are forced to wait a long time (even more than 8 hours), leading to discomfort, an increased risk of infections and severe difficulties in respecting the timetable. Another problem reported is HSCT patients are not provided with Low Bacterial Diet (LBD) during the wait.

Clinical care issues

Clinical and care aspects resulted equally important (135/814). In their narratives, patients reported signs and symptoms played a leading role (82/135) and how, in particular, patients fear post-HSCT fever.

“When I had flu, and this can happen to anyone, I was really scared, and I thought to myself “Hopefully I will make it!...”.

Other patients outlined symptoms of *fatigue*, which is often considered integral part of oncological disease, chemotherapies and/or related depressive conditions. *Fatigue* prevents from returning to normality. Moreover, patients reported serious difficulties in nutrition frequently leading to severe weight loss.

“You might get infected, you might have stomachache, backache. I had to take many pills every day. I could not eat I lost 22 Kg ...”.

Patients declared they appreciated “a patient-tailored approach” by healthcare staff, in particular as concerns the clinical symptoms management.

Relational issues

Regarding care pathways, the majority of patients (11/13) attributed a particular importance to the social aspects (131/814), above all the family presence (mothers, sisters and children), defining this relationship as one of the most important elements to face the disease and the most frequently mentioned topics were Family (42/131) and Familiar Relationship (41/131).

Diseases leading to HSCT involve not only patients but their families too. When the transplant is performed outside their region, the entire family has to transfer and adapt to a new social reality, especially when involving younger patients.

“Everyone got a little crazy, my father, my mother ...”.

An interesting aspect emerged from data analysis was regarding the social reports that the patients installed among themselves. The patients speak, frequently in a veiled manner, about other patients eventual deaths.

“Along this pathway, I unfortunately lost many dear friends ... they are with God now”.

“I met many people who are now dead, each person is unique ... unfortunately that's life...”.

A few patients spoke about their friendship with another patient who later died.

“You meet a person of your own age, then create a rapport in hospital that is more than a friendship. Because you are in the same situation, you emphasize but hide your feelings. I don’t know. (when she died) It was really ugly because we were friends also out of the hospital...”

Notes on interviews

Some patients, at the end of their interview, even though their opinion was not requested, gave a positive evaluation of their experience on NBM, underlining it had been useful to narrate their experience:

“... I’m very pleased I met you ...” “... I liked this. Sometimes it’s helpful to talk...”

Discussion

Our study showed how narrative approach demonstrated to be appropriate for the assessment of HSCT patients’ experiences, during the care pathway. Issues were analyzed and highlighted well beyond clinical care and dealing with psychosocial and relational aspects.

Moreover, we realized the different ways patients experience organizational and structural difficulties of healthcare settings and we learned how these issues can impact on outcomes (21).

The most frequent topics in patients’ narrative were psychological needs they have been experiencing. LBL room isolation had a great impact on their minds with patients reporting they had emotional problems due to their stay and treatment related effects. Religious belief was one of the most recurring topics in their narratives. Independently of HSCT timing, many patients felt “lucky” describing themselves as having “miraculously survived” hematologic and oncological diseases. Especially because they had considered the diseases as incurable and fatal. At diagnosis some patients knew nothing about the disease, hematopoietic stem cell(HSC) donation and its International Registry. This suggests there are still many misconceptions regarding HSCT healing and treatment and insufficient information on HSC donation.

A fundamental topic was the patient-nurse ratio in the LBL room. Patients considered a nurse’s presence 24 hours a day very important and useful in overcoming discouragement and loneliness. The 1:2 ratio internally of HSCT unit demonstrated to be paramount not only for care quality but also bettering educational and psychological support. As concerns improved organization and care for HSCT patients at Transplant Center, where our research was carried out, we suggest the following measures, which we deduced from our analysis of patients’ recommendations and needs:

- A dedicated area available for outpatients during HSCT follow-up;
- A better follow-up schedule, in order to reduce waiting times and avoid overbooking;
- Sufficient staff to help patients to resolve bureaucratic problems
- Psychological support for patients and care givers during the pathway;
- Psychological support to healthcare professionals, in order to improve care quality and prevent burn-out (22, 23).

We therefore consider opportune the setting up of a patient group supported by a psychologist or counselor permitting a deep analysis of the various issues arisen and the sharing of useful information. We suggest the setting up of a HSCT network similar to established experiences such as Rome Transplant Network (24) so as to share HSCT structures and organizations (apheresis laboratory, HSC manipulation areas and cells preservation equipment), favoring a concrete collaboration to improve human and economic resources, offering shared care-pathways, and respecting the patient decisions including the transplant center choice.

This work was performed in only one structure, it could be interesting to repeat the experience in other centers to verify the results. Data shown in this qualitative research could be useful to program further studies (qualitative, quantitative or mixed) in order to better analyze this topic.

Nevertheless, our results suggest the usefulness of a narrative model in HSCT patient care pathway, in order to help professionals understand the patients needs, starting from their narratives to how they lived the disease. Although retrospective recall might have disturbed the accuracy of participants’ narratives, all

patients recalled their hospital stay as an essential life experience. An integration of narrative and scientific approaches could be useful in order to improve therapies' effectiveness, promote organizational patterns of service and care, also providing new professional opportunities to physicians and nurses.

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