Narrative Based Medicine: a digital diary during chemo/radiotherapy treatment to personalize cancer patients care (pilot study)

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Background: Narrative-based medicine is a well recognized methodological clinical approach (1,2); however, in the age of patient (P)-centered care, very few data evaluating the role of theme-oriented P narration applied to the path of cure exists.

Objective: Evaluating feasibility (F) and utility (U) of a model integrating P theme-oriented narratives with clinical data during chemotherapy (CT) or radiotherapy (RT) treatment in cancer P.

Table 1. Patients general characteristics

PATIENTS CHARACTERISTICS	INVITED	PARTICIPANT
	N.	N. (%)
Population size	46	31 (67)
Gender (M/F)	8/38	5/26
Median age (range) by treatment	55 (31-79) <i>CT</i>	58 (31-79) <i>CT</i>
	52 (31-73) <i>RT</i>	48 (31-67) <i>RT</i>
Cancer site:		
Breast	28	20 (71)
Colo-rectum	12	6 (50)
Other	4	2 (50)
Treatment group:		
CT (health care professionals: 2 oncologists)	26	15 (58)
RT (health care professionals: 5 nurses)	20	16 (80)
Narrative path: prompts with replay		168/202 (83)

Patients and Methods: From May 2017, 46 P affected by cancer, undergoing CT or RT at the IRCCS "Regina Elena" National Cancer Institute, Rome, were asked to participate (Table 1). Eligible criteria were: age ≥18 years, availability of an electronic device and an email address. P told about him/herself in a digital narrative diary (DNM), a platform for the application of narration in clinical practice, using a guided narrative path. Two oncologists (CT group) and five nurses (RT group), read the stories, shared and used them to personalize the cure. P access was gained by invitation from health care professionals (HCP) in accordance with health data confidentiality criteria. Ethics Committee approved the study. A written informed consent was required. Questionnaire: a semistructured questionnaire investigating F and U items was administered at the end of the study period (8 months) to both P and HCP. P-F items were: friendliness and easiness to diary (to be handle), its adequacy in reflexive writing, compliance with diary; HCP-F items were: diary friendliness and easiness, time management, quality of visit. P-U items concerned: communication, cure relationship, awareness, self-confidence, empowerment; HCP-U concerned: P communication and relationship, therapeutic alliance, illness/disease knowledge. Statistycal analysis: a mixed qualitative-quantitative analysis methodology was used, including basic content methods (i.e. theme category, word cloud) and Likert scale metric (level of agreement/ disagreement ranging from 1to 5).

Results: All patients agreed to participate and 31(67%) used the diary: they were mostly female (84%) and middle-aged on average. A high PCP-F and U medium scores emerged (Table 2A). P-F medium score was high too; however P-U score was strongly related to HCP behavior, ranging from 3,6 (if scarce or no feedback) to 4.7 (regular feedback) (Table 2B). The strongest advantage reported by HCP was the opportunity to disclose individual relevant data for cure, otherwise not detectable. Both P and HCP strongly suggested the introduction of the diary in clinical practice.

Table 2 A-B. Evaluation of the digital narrative diary by (A) HCP and (B) P

(A) HEALT CARE PROFESSIONALS ASSESSMENT	Oncologists Likert score (average)	Nurses Likert score (average)
FEASIBILITY (F)		
Diary frieandliness	4,7	4,6
Diary immediacy and comprehensibility	3,7	4,6
Time management	4,5	4,2
Optimazing clinical examination (lenght)	4,5	4,2
Optimazing clinical examination (quality)	4,5	4,6
UTILITY (U)		
Communication improvement	4,7	5,0
Care relationship improvement	4,7	5,0
Deeping in patients knowledge	5,0	4,4
Therapeutic alliance improvement	4,2	4,8
To focus on history of care	3,7	4,8

(B) PATIENTS ASSESSMENT	CT group Likert score (average)	RT group Likert score (average)
FEASIBILITY (F)		
Diary frieandliness	4,5	4,8
Diary immediacy and comprehensibility	4,6	4,8
Adequacy of own computer skills	4,4	4,0
Opportunities to express oneself	4,6	4,7
Opportunities to express personal data	4,4	4,2
otherwise not comunicable		
UTILITY (U)		
Possibility to express own point of view	4,5	4,4
Perception of effective tacking in charge	4,0	4,4
Awareness improvement	3,8	4,2
Empowerment and self-confidence improvement	3,6	3,7
Care relationship improvement	3,8	4,1
Suggestion for the introduction in clinical practice	4,5	4,6

Conclusions: The study provided data supporting the need of integrating P narratives with clinical data, encouraging further research. At the same time, health care professionals narrative competence, the involvement of the whole care team and an appropriate health system organization are required (3).

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