

# A narrative digital diary applied to chemo/radiotherapy treatment to personalize cancer patient care (*pilot study*)

MC Cercato<sup>1</sup>, E Colella<sup>2</sup>, A Fabi<sup>2</sup>, I Bertazzi<sup>2</sup>, BG Giardina<sup>3</sup>, P Di Ridolfi<sup>3</sup>, M Mondati<sup>3</sup>, P Petitti<sup>3</sup>, L Bigiarini<sup>3</sup>, V Scarinci<sup>4</sup>, A Franceschini<sup>5</sup>, F Cognetti<sup>2</sup>, G Sanguineti<sup>3</sup>, C Cenci<sup>5</sup>

<sup>1</sup>Servizio di Epidemiologia e Registro Tumori, <sup>2</sup>UOC Oncologia Medica 1, <sup>3</sup>UOC Radioterapia, <sup>4</sup>Biblioteca Digitale «R. Maceratini» IRCCS Istituto Nazionale Tumori Regina Elena, Rome. <sup>5</sup>Digital Narrative Medicine (DNM s.r.l.), Rome.

## 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 (3).

## 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. Patient general characteristics

PATIENT CHARACTERISTICS	INVITED N.	PARTICIPANT N. (%)
Population size	46	31 (67)
Gender (M/F)	8/38	5/26
Median age (range) by treatment	55 (31-79) CT 52 (31-73) RT	58 (31-79) CT 48 (31-67) RT
Cancer site:		
Breast	28	20 (65)
Colo-rectum	14	9 (29)
Other	4	2 (6)
Treatment group ( <i>health care professionals</i> )		
CT (2 oncologists, 1 nurse)	26	15 (58)
RT (5 nurses)	20	16 (80)
Narrative path: prompts with reply		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  $\geq 18$  years, availability of an electronic device and an e-mail 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 (4). Eight health care professionals (HCP) (CT group: two oncologists (Ph), one nurse (N); RT group: five N) read the stories, shared and used them to personalize the cure. P access was gained by invitation from HCP in accordance with health data confidentiality criteria. Ethics Committee approved the study. A written informed consent was required. Questionnaire: a semi-structured 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. Statistical 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 1 to 5).

## Results

All patients agreed to participate and 31 (67%) used the diary: they were mostly female (84%) and middle-aged on average. F and HCP-U medium scores were high (Table 2 A-B). P-U single score was related to HCP feed-back to narration: ranging from 3,6 (scarce) to 4.7 (regular). N are considered the guarantors of the continuity of care. HCP strongest reported advantage were: the opportunity to disclose individual relevant data for cure, otherwise not detectable (Ph) and to strengthen communication and care relationship (N). 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) HEALTH CARE PROFESSIONALS' ASSESSMENT	Oncologists' Likert score (average)	Nurses' Likert score (average)
<b>FEASIBILITY (F)</b>		
Diary friendliness	4.7	4.6
Diary immediacy and comprehensibility	3.7	4.6
Time management	4.5	4.2
Optimized clinical examination (length)	4.5	4.2
Optimized clinical examination (quality)	4.5	4.6
<b>UTILITY (U)</b>		
Improved communication	4.7	5.0
Improved care relationship	4.7	5.0
Deeper knowledge of patient	5.0	4.4
Improved therapeutic alliance	4.2	4.8
Focus on care history	3.7	4.8
<b>(B) PATIENTS' ASSESSMENT</b>		
	CT group Likert score (average)	RT group Likert score (average)
<b>FEASIBILITY (F)</b>		
Diary friendliness	4.5	4.8
Diary immediacy and comprehensibility	4.6	4.8
Adequacy of one's own computer skills	4.4	4.0
Opportunities to express oneself	4.6	4.7
Opportunities to provide personal information otherwise not-communicable	4.4	4.2
<b>UTILITY (U)</b>		
Possibility to express one's own point of view	4.5	4.4
Perception of effective taking charge	4.0	4.4
Improved awareness	3.8	4.2
Improved empowerment and self-confidence	3.6	3.7
Improved care relationship	3.8	4.1
Recommendation to introduce into 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).

## REFERENCES

- 1) Rita Charon. Narrative Medicine. A model for empathy, reflection, profession and trust. JAMA 2001; 286: 1897-1902.
- 2) Consensus Conference : "Linee di indirizzo per l'utilizzo della medicina narrativa in ambito clinico-assistenziale, per le malattie rare e cronico-degenerative", 11-13 giugno 2014, ISS, Roma. <[http://old.iss.it/binary/cnmr4/cont/Quaderno\\_n\\_7\\_02.pdf](http://old.iss.it/binary/cnmr4/cont/Quaderno_n_7_02.pdf)>
- 3) Cercato MC. Narrative medicine in the oncological clinical practice: the path from a story-telling intervention to a narrative digital diary. Recenti Prog Med. 2018 Jun; 109(6):324-327.
- 4) DNM-Digital Narrative Medicine <http://digitalnarrativemedicine.com/it/>