

THE INFLUENCE OF NARRATIVE MEDICINE TECHNIQUES ON THE ROLES OF POTENTIAL PATIENT AND FUTURE CAREGIVER – A PILOT STUDY

A INFLUÊNCIA DAS TÉCNICAS DE MEDICINA
NARRATIVA NOS PAPÉIS DE POTENCIAL PACIENTE
E DE FUTURO CUIDADOR - UM ESTUDO PILOTO

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ABSTRACT

The emergent field of the Medical Humanities defends the introduction of training in the humanities in healthcare contexts. Considering Narrative Medicine as one of the areas of the Medical Humanities, a pilot study was conducted with a group of 9 students (Medical and Humanities) to gain some insight as to if/how training in Narrative Medicine techniques (namely, *close reading* of and *creative/reflective writing* on literary narratives on the thematics of health) could promote changes in participants' perceptions of their potential roles as patients or caregivers. Alterations were assessed using semi-structured, focus-group interviews carried out after training. Qualitative thematic analysis was used to examine interview responses. The interviews demonstrated that participants perceived that the training had enhanced their capacity to fulfill their patient and caregiver roles. Potential patients expressed a desire to interact more fully and efficiently in healthcare relationships and future healthcare professionals expressed a desire to attend their patients more comprehensively. Moreover, participants' responses spoke to the potential benefits of using Narrative Medicine literary analysis techniques with mixed groups. The findings of this study are presented within the context of contemporary theories on the Medical Humanities and Health Humanities.

Keywords: Narrative Medicine. Medical Humanities. Close reading. Reflective writing.

RESUMO

O campo emergente das Humanidades Médicas defende a introdução de formação nas humanidades nos contextos da saúde. Considerando-se a Medicina Narrativa uma das áreas das Humanidades Médicas, foi realizado um estudo piloto com um grupo de 9 estudantes de Medicina e Humanidades, de modo a explorar como o treino em técnicas de Medicina Narrativa (i.e., a *leitura cerrada* e a *escrita reflexiva* de narrativas literárias na temática da saúde) pode promover mudanças nos seus potenciais papéis de paciente ou cuidador. Após o treino foram realizadas entrevistas de grupo de foco para explorar a percepção dos participantes sobre as mudanças decorrentes daquele treino nos seus potenciais papéis de paciente ou cuidador. As respostas às entrevistas foram sujeitas a uma análise de conteúdo temática, tendo revelado que os participantes perceberam que o treino potenciou as suas capacidades de desempenho dos seus papéis de paciente e cuidador. As respostas suportam os benefícios potenciais das técnicas de análise literária da Medicina Narrativa com grupos compostos por profissionais de saúde e pacientes, sugerindo que isso pode ajudar os profissionais de saúde a atender melhor aos seus pacientes, mas também que pode permitir que os próprios pacientes participem de maneira mais completa e eficiente na relação de cuidado. Os resultados são interpretados no contexto das teorias contemporâneas das Humanidades Médicas e das Humanidades da Saúde.

Palavras-chave: Medicina Narrativa. Humanidades Médicas. Leitura cerrada. Escrita reflexiva.

INTRODUCTION

Incorporating practises that can assist healthcare professionals in providing the best care possible in contemporary and future medical scenarios is at the centre of current debates on health care education and training. In this article we will look at the arguments presented by the Medical Humanities in general and Narrative Medicine in particular within this context. Therefore, before discussing the pilot study we will begin this article with a brief overview of the history and development of the Medical Humanities from the 20th century to the present. We will then offer an introduction to Narrative Medicine and its techniques as two such techniques – *close reading* of and *creative/reflective writing* on literary narratives – were used in the pilot study¹ carried out with Medical and Humanities students². This study asked the research question: if/how *close reading* of and *creative/reflective writing* on literary narratives on the thematics of health can promote changes in the roles of the participants in the caregiving relationship. The technical parameters of the study – its specific objective and importance – will then be laid out. The basic methodology is presented in a Method section which describes the participants, the intervention, assessment and data analysis procedures. The Results and Analysis section describes and interprets the results and the Final Considerations section will summarise the findings, indicating the limitations as well as future possible research.

THEORETICAL FRAMEWORK: MEDICAL HUMANITIES & NARRATIVE MEDICINE

Historian of science, George Sarton, introduced the term Medical Humanities in 1948 to permit the conjoining of medicine and the humanities under a unifying umbrella term at a time when approaches to medical education and training – including the discussion of the potential role of the humanities and multidisciplinary approaches in this field – were being debated (HURWITZ, 2015, p.14). Two decades later, in 1973, the Medical Branch of the University of Texas at Galveston founded the first Institute devoted to Medical Humanities (HURWITZ, 2015, p22). Since then the field of Medical Humanities has played an important role in making the humanities central to many medical programs in the USA and

¹ This pilot study was carried out within the context of a Masters thesis in Educational Psychology (3rd author) and in connection with the Medical Humanities Research Project based at the ULICES (University of Lisbon Centre for English Studies).

² This group resulted from open invitations for participation in a Narrative Medicine study issued in a Medical Faculty and a School of Arts & Humanities.

Europe (AHLZEN 2007). For instance the Association of Medical Humanities (AMH) founded in the UK in 2000 currently lists 17 Medical Humanities programs in British and Irish universities as well as five full degrees – 1 BA, 3MAs and 1 BSc (ASSOCIATION OF MEDICAL HUMANITIES).

However, the connection between literature and medicine far precedes the establishment of the Medical Humanities as a field. In fact, it seems that physicians have always been drawn to poetic expression as is attested by Mary Lou McDonough's compilation of the poetry of one hundred doctors: *Poet Physicians, An Anthology of Medical Poetry Written by Physicians* (1945). Perhaps what is more revealing is not the volume itself, but rather its reception by the medical community as illustrated by Thomas Keys' review in the *Bulletin of the Medical Library Association* (1945). Keys began the review indicating that it is the very nature and demands of the medical professional that leads physicians to write poetry. He also refers to the role that literary writing had played historically in transmitting knowledge from one generation of medical practitioners to the next:

It is not surprising that many physicians have contributed to the poetic literature. Whether it is an expression of their insight into the workings of the human mind brought about by their appreciation of personal contacts or due to a disciplined ability in general is hard to determine.

[...] In the beginning, certainly, and long before the era of the printing press, poetry was of great practical importance. For, being transmitted orally from generation to generation, it was a way of preserving our cultural heritage. (KEYS, 1945, p.226)

Moreover, since the birth of modern medical training programs at the end of the 19th century leading medical educators including William Osler have considered the study of literary classics and medical biographies fundamental to the complete education of doctors, proposing that this study could help young physicians to bridge the gap between theoretical learning and practical application (OSLER, 1908).

Osler's thinking is echoed in contemporary generalistic studies that have been carried out to look at the potential role that the humanities may play in health care education. For instance, Kaptein and Lyons suggest "Novels and other creative endeavours offer potentially rich sources of knowledge, empowerment and enlightenment, and their use in health psychology could be invaluable" (KAPTEIN and LYONS, 2009, p.169). They further propose that exposure to cultural productions, from theatrical performances to literary texts, can provide health professionals with the competences required for practicing in today's global world because these can offer much-needed contact with cultural realities outside of the mainstream. Moreover, Watson's recent empirical study demonstrated that when students from the health sciences read for leisure their empathy, understanding, thinking and communication

skills were further developed (WATSON, 2015). Building on prior research, including Kidd and Castano (2013), and Black and Barnes (2015), Pino and Mazza's extensive study demonstrated that attentive reading of fictional novels can indeed enhance empathy levels among psychology students (PINO and MAZZA, 2016). Furthermore, Ghias and collaborators observed that medical students perceived that the introduction of Humanities and Social Sciences seminars in their medical training programs had helped to broaden their comprehension of the carer-patient relationship (GHAS and collaborators, 2016).

In recent years Paul Crawford and his team have appealed to the inclusion of training in the humanities not only for all the healthcare professionals involved in caring, but to also extend this practise to informal carers and service users – namely the patients themselves (CRAWFORD, 2010). They suggest the broader term Health Humanities as the future of Medical Humanities, proposing that “despite considerable achievements in the medical humanities a more inclusive and applied approach to healthcare is vital” (CRAWFORD et al, 2010, p.8). We consider that Narrative Medicine has great potential as an inclusive application as it places the narrative of the patient and the caregivers' interpretation of this at the centre of the healthcare relationship. It suggests “if sickness unfolds in stories, both when the patient tells of symptoms and the doctor hears and retells them, then narrative practice might occupy a central role in the lived experience of being ill and caring for the sick” (CHARON, 2015: 95). Thus, it can be seen to support Crawford *et al's* suggestions.

Specifically looking at the proposals of Narrative Medicine, we can see that it suggests that interaction with health narratives through *close reading* and *creative/reflective writing* composed “in the shadow” of the text read, enhances carers' attention and representations skills, thus their capacity to comprehend patients' stories of illness and represent these externally. It also proposes that close reading of participants' own texts can contribute to the capacity to create successful affiliations with all the intervenients in healthcare relationships (CHARON, 2001, 2006, 2015).

When it comes to extracting information from written texts, *close reading* has been used for millennia across myriad disciplines, from comprehension exercises in education to theological research, as a meaning-making instrument (SISSON and SISSON, 2014). Therefore, practise of *close reading* in medical training could hone the skills required to extract meaning from narratives transmitted in a medical consultation. Rita Charon, the founder of the Narrative Medicine methodology, goes even further proposing that “attentive listening to oral language is akin to *close reading* of a written text, and training in *close reading* is seen to ‘translate’ into improved attention in listening to oral language” (CHARON, 2015: 99). But Narrative Medicine's proposals go beyond enhanced meaning-making skills, suggesting that training healthcare personnel in skills such as *close reading* and *reflective writing* not only enhances

the quality of care given, but also the caregiver's sense of fulfilment in the patient-carer relationship (CHARON, 2001). The perspective of Narrative Medicine aligns with that of Narrative Psychology (e.g., BRUNER, 2004), which suggests that narratives produced by cultural objects (including literary and art narratives) function as models that influence how individuals organize and create their experience. This of course could be seen to include the health patient and carer experience.

Moreover, studies carried out recently in healthcare settings to evaluate the effects of directed reading and writing activities – similar to *close reading* and *creative/reflective writing* – have shown very positive outcomes, validating Charon's proposals. For instance, when physicians were trained in guided *reflective writing*, contemplation capacities were promoted and empathy enhanced (MISRA-HEBERT et al. 2012). Furthermore, controlled experiments have demonstrated that encouraging patients to write reflectively about stressful experiences had a significant positive effect on the severity of symptoms experienced by patients suffering from asthma and rheumatoid arthritis (SMYTH et al., 1999). Writing about prior trauma also boosted immune response to Hepatitis B vaccination among medical students when they were immunized (PETRIE et al., 1995). These studies speak to the benefits of using directed reading and writing activities in healthcare contexts.

THE PILOT STUDY

This pilot study aimed to explore the participants' considerations of how the intervention – reading fictional, literary texts on the thematic of healthcare and writing about these – had impacted on their perception of their roles of patient and carer. The importance of this study is that it contributes to an empirical grounding for the possibilities claimed for this kind of intervention. Moreover, it permits the collection of information from future carers and potential patients' on their individual perceptions of possible changes brought about by this kind of intervention.

This pilot study was developed in the aftermath of a broader study carried out with Humanities students (HS) and Medicine students (MS). This experimentally evaluated the effects that the intervention (training in *close reading* and *reflective writing* of literary narratives on the thematics of health) had on the quality of analysis produced by students (DUARTE et al., 2020).

METHOD

An intervention inspired by Narrative Medicine practices was applied with a mixed group of HS and MS. The group was composed of 9 university students: 2 males and 7 females, mostly in the 3rd year of their studies ($M=3$; $SD=.44$) with a statistical mean age of 22.5 years ($SD=3.68$). 7 participants were HS and 2 were MS. Informed consent was obtained and confidentiality was assured. The study was approved by an Academic Institution's Deontological Commission.

The group participated in three sessions of around fifty-five minutes over a period of three weeks. They learned and used *close reading* of and *creative/reflective writing* applied to excerpts of literary narratives on health. The excerpts dealt with different aspects of illness and of the relationship between carer and patient. The excerpt from *The Whereabouts of Eneas McNulty* by Sebastian Barry (1998) illustrated the observation of sudden illness from the outside; the section from *Heart and Soul* by Maeve Binchy (2008) demonstrated the experience of illness; and the text from *The English Patient* by Michael Ondaatje (1992) focused on the role of the carer.

In each session, following Narrative Medicine procedure (CHARON et al, 2016), participants were given a brief introduction to the text to be read. This was then read aloud, slowly and expressively, as participants read it silently and freely marked (i.e., underlined and/or noted) the aspects they considered as relevant to them. Subsequently, each participant was invited to speak about the sections they had highlighted and these were discussed by the group, with a view to permitting participants comprehend selections and consolidate personal connections with the text. As this process developed, the facilitator called participants' attention to the literary techniques and language used in the text (e.g., metaphor; irony, etc.), because these were often present in the sections selected for discussion. The facilitator's purpose here was not primarily to teach literary analysis skills, rather it was to illustrate that these devices are used to *say that which cannot be said easily in words*; a strategy often used by patients when they cannot/do not know how to describe what is happening in their bodies. Curiously, as the sessions progressed the heterogeneous nature of the group led to increasingly lively discussions as participants became increasingly aware of how their different perspectives and backgrounds enriched the reading and understanding of the texts being analysed.

In each session, following *close reading*, participants carried out a *creative/reflective writing* exercise by writing freely for five minutes (i.e., in any form of their choice: text or loose sentences; fiction or non-fiction, prose or poetry) on the basis of a prompt related to the text previously read (e.g., the prompt used to Ondaatje's text was "Caring ..."). Subsequently, participants were free to read their writings aloud

to the rest of the group, and participants' written texts were discussed technically using *close reading* techniques.

The week after the intervention ended two distinct semi-structured focus-group interviews – one with the HS (potential health patients) and another with the MS (future health carers) – were carried out to obtain a qualitative analysis of the results of the training, with a view to gaining insight into the perceptions that participants had on the intervention's impact on their role as health carers (in the MS) or as health patients (in the HS). The interviews were implemented on the basis of prepared scripts covering a variety of areas: general perception of the intervention; general changes provoked by it; its impact on general and specific aspects of the role as health carer (for the MS) or the role as health patient (for the HS).

A thematic analysis (MILES and HUBERMAN, 1994) was carried out to analyze participants' answers regarding their perceptions of the intervention's impact on the role of patients or carers. The answers to the interviews were first deductively segmented in *units* on the basis of a thematic criterion that coincided with the *areas* of the interview scripts. Resulting *units* were then inductively categorized, in order to construct a categorizing system that was then applied for a second loop categorization of all the *units*. Validity of the categorization system was assessed as this was applied to the totality of segmented *units* by an independent *judge* and calculus of agreement with categorization was obtained (agreement coefficient = 97.1%).

RESULTS & ANALYSIS

The results refer to participants' overall perception of wide-ranging changes provoked by the intervention, as well as its impact on general and specific aspects of the role as health carer (for the MS) or the role as health patient (for the HS). As the questions in the interviews were different, the answers will be presented separately for each group in two distinct tables (table 1 and 2). The analysis, however, will be presented together. We will begin with the MS results.

Table 1 - Medicine students' perceived intervention induced changes on their health carer role

Area of Change	Change	Supporting Extract from Interview
Attention	Attention in general (increase in attention in general)	"I changed, [it] drew my attention to some things."
	Systemic (increase in attention to the patient as a whole)	"(...) a person is not only words, there is always something more."
	Attention to discourse (increase in attention to the discourse of the patient)	"I am going to listen with more attention."
Analysis	Interpretation (improvement in the interpretation of the discourse of the patient)	"(...) [it improved] the way in which I interpret what people say."
Diagnosis	Diagnosis in general (improvement of diagnosis in general)	"We have another capacity [for diagnosis]."
Relationship	Relationship in general (improvement of the relationship with the patient)	"It helped me to deal with patients."
Treatment	Individual (improvement of the personalization the treatment of the patient)	"[dealing with] (...) a person as an individual. Every case is an individual case."
	Systemic (treating the patient as a whole person)	"Yes, yes, speaking to other doctors who attend the patient [to coordinate the treatment]."
Identity	Flexibilization (flexibilization in professional identity)	"(...) made me see that I do not have to [only] follow a set reference sheet."
	Humanization (humanization of identity)	"(...) to be a more humane person."

Source: semi-structured focus-group interviews

As can be seen in Table 1, the analysis of MS interviews demonstrated extensive modifications in the perception of the role of health care provider. A general rise in attention was indicated on the part of the caregiver (e.g., "I changed, [it] drew my attention to some things."). An increased attention to patients' discourse, to patients as a whole and to the interpretation of their discourse was also registered (e.g., "I am going to listen with more attention."; "(...) a person is not only words, there is always something more."; "(...) [it improved] the way in which I interpret what people say").

The relevance of an enlarged discourse with other caregivers when reaching diagnosis and prescribing treatment was also noted (e.g., "Yes, yes, speaking to other doctors who attend the patient

[to coordinate the treatment.]”); as was a move towards a more personalized approach at a systemic level to the medical encounter (e.g. “[dealing with] (...) a person as an individual. Every case is an individual case.”). Regarding perspectives on the changes in identity, MS participants registered that the intervention helped the development of a more flexible perspective on professional identity (e.g., “(...) made me see that I do not have to [only] follow a set reference sheet.”) and increased humanization e.g., “ (...) to be a more humane person.”).

Table 2 - Analysis of HS interviews also revealed modifications in participants’ perceptions on their role as health care patients.

Area of Change	Change	Supporting Extract from Interview
Attention	Attention (increase in attention to the condition of patient)	“(...) I will be more alert to the things that are happening/may happen to me [as a patient].”
Comprehension	Valorization (increase in valorization in understanding the condition of the patient)	“I think that it is important to be aware, have an idea of what may be wrong with you [organically].”
Relationship	Attention to Relationships (increase in attention to relationships with carers)	“(...) I will pay more attention to the questions the doctor asks me.”
	Facilitating [Relationships] (increase in motivation to facilitate relationships with carers)	“I will try to facilitate the doctor- patient relationship.”

Source: semi-structured focus-group interviews

The interviews indicated, above all, that participants registered modifications in their understanding of the relevance of self-observation and paying attention to their physical conditions/symptoms as a patient (e.g., “(...) I will be more alert to the things that are happening/may happen to me [as a patient].”). Moreover, altered perceptions of their potential relationship with caregivers were also recorded. Participants registered an increased motivation to cooperate more actively and accurately with caregivers (e.g., “(...) I will pay more attention to the questions the doctor asks me”), and “I think that it is important to be aware, have an idea of what may be wrong with you [organically].”) Ultimately, their appeared to be a greater desire to facilitate interchanges in the patient-caregiver setting (e.g., “I will try to facilitate the doctor-patient relationship.”).

When analysing the group’s perceived changes both in the role of potential health patient and carer; these appear to indicate (to be further verified) that this type of intervention with *close reading* and

reflective writing of literary narratives has the capacity to promote change and contribute to modifying attitudes both in health patients and carers. This proposal is verified by HS's' responses which indicate a more proactive stance in the condition of being a patient and to the relationship with carers. MS's answers suggest an intensification in the orientation towards patients, to the relationship with them, to their narratives, as well as a desire to seek to offer a personalized integrated treatment, and to procure a flexible and humane professional identity.

It appeared that analyzing fictional characters that are health patients and carers, together with their relationships, contexts and stories (especially in a mixed group like the present one), can alert participants to their own roles as a patient or carer, and so influence the way experiences may be organized. This in turn could be seen to encourage alterations in the ways these roles may be played. Not only are these explanatory hypothesis reflective of the proposals made by Narrative Medicine, they are also in keeping with findings from Psychology of Art. The latter suggests that a variety of psychological processes are activated by "reading/interpreting" fictional narratives in general and these can impact on the reader's identity and social roles. These include: deep and selective attention to the narrative (CSIKSZENTMIHALYI, 1992; GERRIG, 1993; OATLEY, 2011); empathy and alliance with characters (e.g., KAUFMAN and LIBBY, 2012; PERSSON, 2003); development of *theory-of-mind* and social perception (e.g. MAR et al. 2006; 2010); comprehension of characters and narrative (e.g. OATLEY, 2011); *vicariously learning* from characters (e.g., BRUNER, 2002, 2004); and moral development (HAKEMULDER, 2000).

FINAL CONSIDERATIONS

In summary the intervention, which introduced a group of potential health patients and carers to *close reading* of and *creative/reflective writing* on literary narratives on health, attests to the general value of this practice. Therefore, this study contributes to the empirical grounding of the benefits of Narrative Medicine (CHARON, 2006). It indicates that introducing (future) health carers to *the close reading of* and *creative/reflective writing on* literary narratives on health (eventually in the context of courses or workshops) offers the prospect of a more complete and rounded approach to healthcare. It also indicates that these practises seem to improve participants' expectations for experiences and relationships in this area. Moreover, introducing (potential) health patients to Medical Humanities education techniques and working with mixed groups including players "from different sides" of the healthcare relationship appears to have the potential to bring benefits to the care relationship as this offers all the members in the care context greater awareness of their own role and the role of the other in this environment supporting the

proposals of Crawford and his team (CRAWFORD et al, 2010). Thus, it can be proposed that this type of training may contribute to the amelioration of health practices and systems.

Nevertheless, the results of this exploratory study must be carefully read considering the reduced number of participants, and the imbalance between HS and MS in the sample. The outcomes may allow generalization to theory but they do not permit a generalization to the population. A future implementation of similar studies with broader samples of participants (and not only potential but also actual health patients and carers) would be required for the latter. Moreover, future studies should also consider a controlled (before-after) measurement of participants' perceptions of their roles of patients and carers; this was absent here. Also, if one considers the concept of multiple intelligence, we know that individuals can be stimulated in different ways by different art forms. Thus, it would be relevant to carry out similar studies with artistic objects from other and mixed domains. However, while the findings of this pilot study may be limited due to the sample size, we consider that they are indeed encouraging and the work should be continued.

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