Literature and science: a different look inside neurodegeneration

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Awareness of the mutual impact of humanities and medical sciences has long been raised, and appropriate steps have been taken to implement this understanding in the medical curricula of both the United States and United Kingdom (8). The German curricula of medicine and pharmaceutical sciences, in contrast, do not currently envision the integration of humanities modules in their syllabi. However, being exposed to a heavily chemistry-focused curriculum, neither professional pharmacy students nor pharmacy PhD students undertaking research into biochemical and molecular disease processes are well informed about the nature of the relevant disease. This is especially true in terms of its impact on patient perception and personality, since natural and social sciences generally do not provide the humane perspective (4, 7). Using narrative texts gives the student the opportunity to empathize with positions s/he might otherwise never take (9). In fact, approaching specific illnesses or ailments from the narrative perspective complements rather than competes with the (patho)physiological or biological approach to the understanding of illness and suffering.

Given our current situation, along with the knowledge that integrating narrative texts into healthcare education has proved to be highly beneficial (1, 2), we devised, inspired by earlier success in the reorganization of a physiology course toward more practical experience and student involvement (11), an optional “Literature and Science” module for pharmacy PhD students who conduct research into acute or chronic neurodegenerative disorders, such as fetal alcohol syndrome, stroke, and dementia. For the first year of study, the narrative presentation of Alzheimer’s disease (AD) was chosen, primarily because this condition is one of the core areas of biochemical/molecular research in the students’ immediate environment; the course would complement data discussion rounds and journal clubs focusing on this illness. In addition, pharmacological as well as neurochemical aspects of the condition are the course instructor’s scientific expertise (6, 12) and focus of recent medical humanities research (9, 10). As such, the instructor’s qualifications strongly supported a thorough crossing of disciplines in the first year of the course. Finally, this course also aimed at providing pharmacy PhD students, who frequently work in the pharmacy at night or weekends, with additional patient interaction skills. Given that other neurological conditions, such as depression or anxiety, are already the focus of undergraduate lectures in the module pharmaceutical care, the concentration on AD seemed all the more purposeful.

This course pursued the following general goals: 1) enhancing the students’ empathy with the sufferer (both caregiver and patient); 2) furthering their understanding of the broader meaning of the disease and its consequences; and 3) widening their field of vision, giving them additional opportunities for reading new books, exposing them to alternative avenues of thinking, and providing an occasion and platform for discussion. As such, the present work introduces a teaching strategy that, in its optional nature and in being held for a small class, represents the necessary first step and foundation to integrate medical humanities in environments where “literature and medicine” play only marginal roles.

Course Concept and Contents

Students met once every 2 mo to allow for sufficient reading time alongside research and teaching duties. The meeting time was set for Thursday late afternoons, i.e., toward the end of the main working hours and into the second half of the week so as to ensure that students would feel more “on top” of their research undertakings and emotionally free to dedicate time to work outside their core PhD project. In addition, this strategy avoided breaking up experimenting periods and times when participants would be too distracted or drained to engage. To ensure continuity and quality of the discussions, students were encouraged to commit themselves to the course for its entire duration of initially 1 yr. The number of participants oscillated between five and eight students, with intermittent attendance of Masters-level students who attended single sessions.

The seminar sessions were held as spontaneous discussion rounds. While the course initiator suggested the reading material and devised the five session topics, she saw herself much rather as an engaging participant than as a guiding teacher. The discussion usually centered directly around disease-related issues that were broached in the narratives and literary themes as well as questions as to how literary aspects potentially supported the narrators’ notion of their condition. Table 1 shows an overview of the course concept, i.e., the topics of the five seminar sessions, their main objectives, and the two centrally addressed issues in each session.

The relevant narratives were communicated 2 mo before the meeting date or at the meeting itself for the next course session. The selection of texts aimed at bringing together fictional and nonfictional narratives relating to various aspects of AD and was based on recommendations for texts suitable for the medical training curriculum as suggested by others (5). In fact, the texts gave insight into both the caregiver’s and patient’s point of view and the societal perception of the illness. Usually, two or more different texts were suggested, with the idea being that students would study at least one of them so that the discussion could evolve from a comparison of the texts. A complementary research paper (scientific, clinical, or sociological in orientation) was handed out before each session. These papers were generally intended to illustrate a specific aspect broached in one of the narratives or give insight into the seminar topic from the non-narrative point of view. Table 2 shows a summary of the reading material. Questions as to how
Table 1. Course topics, objectives, and key elements in each session

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<th>Objective</th>
<th>Key Elements</th>
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<td><strong>Session 1: AD in fiction</strong></td>
<td>1. Presentation of the illness and aspects of diagnosis and care 2. The use of the motif of dementia and memory loss as a plot device</td>
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<tr>
<td><strong>Session 2: the AD caregiver’s view</strong></td>
<td>1. The demands and strain placed on dementia caregivers 2. Aspects of life writing: ethics and gender-related issues</td>
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<tr>
<td><strong>Session 3: the impact of AD on the caregiver and patient</strong></td>
<td>1. The interactions between and mutual perceptions of caregiver and patient 2. The power of fiction (compared with that of life writing) to focus our attention</td>
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<tr>
<td><strong>Session 4: the AD patient’s view</strong></td>
<td>1. The patient’s outlook and personal confrontation with dementia and their agenda, including aspects of gender and collaborative writing 2. The patient’s viewpoint in fictional accounts</td>
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<tr>
<td><strong>Session 5: AD in film</strong></td>
<td>1. The presentation of AD in visual compared with textual narratives 2. The ethicality and consequences of presentation</td>
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This synopsis introduces the topics and objectives of each course session and highlights the two core elements addressed 1) directly relating to the actual gain of knowledge in clinical terms and 2) opening avenues for more literary approaches to the condition, AD, Alzheimer’s disease.

the different sessions linked together, how the narrative and non-narrative texts complemented each other, and how the sessions would impact on professional practice are addressed below.

Suter’s detective story provided a stimulating introduction to the course as a whole and the illness in particular, in part because it places a strong emphasis on the enabling powers of the disease. As such, the session focused on aspects of patient autonomy and independence, with these insights encouraging a more positive and enabling attitude toward patients in the professional practice. Since these considerations are closely linked to caregiver approaches, as also emphasised by the scientific paper, the discussion eventually moved toward aspects of caregiver burden, which led over to the second session. Bayley’s account, a well-acknowledged point of reference for clinicians and gerontologists, addresses various aspects of being a caregiver. A comparison to Grant’s text directed the discussion to gender-related issues and the author/narrators’ agenda and choice of presentation. The insights from this reading help educate the pharmacist to specific caregiver needs.

In pondering the question as to the caregiver’s prerogative of telling the patient’s story, the third session addressed the question as to the relationship between the burdened caregiver and the afflicted patient from a fictional viewpoint. Specifically, Held’s and Gerster’s texts provided the basis for further exploration of the spousal burden compared with the adult child burden, addressing the deeply personal and individual aspects of dementia and its care that are not accessible through, e.g., the scientific or clinical literature handed out for the same course session. With respect to professional practice, this session further enhanced the understanding that patient and caregiver perspectives differ significantly, especially given the discrepancy in outlook and agenda. The fourth session attended to the core question of the patients’ attitude toward the confrontation with a terminal illness and their perception of their situation in family and society. With the awareness that AD patients are unable to tell about the final stages of the disease, the session included the consideration of Genova’s fictional viewpoint, which gives insight into the part of the story that lies beyond the patient’s tale. These reflections will further encourage empathy toward the increasingly challenged but still “able” patient and draw attention to their needs. Wiltshire’s article then served to raise awareness of the increasing array of illness narratives.

Finally, our course concluded using the highly appraised, although controversial, film “Iris.” The film brought to light many of the previously discussed narratives of patient and caregiver and provided an excellent vehicle for a rich culminating discussion.

Course Perceptions and Outlook

To encourage students to engage actively with this first attempt to cross disciplines in the life science research environment, the course was optional, and its organization and timeline respected the students’ research commitments. With these considerations in mind, a quantitative evaluation of the course reception (also with respect to the aims as stated) was deliberately avoided. Instead, all students, who had attended every single seminar session, were asked at the end of the course to provide written comments on the module in general, its contents, and how they viewed its position within their PhD training (Table 3). All students clearly identified the importance of insight into the patient and caregiver’s world of experience, which went beyond the medico-scientific point of view. Likewise, they acknowledged the “mind-extending opportunity” the course provided both in terms of the texts studied and the discussion rounds as such. In fact, the students acknowledged that the narratives as well as the subsequent discussions in this course pushed them to reconsider their personal attitudes and opinions about the demands that the disease places on caregivers and about the actual daily encounters with patients and in the pharmacy. We recognize that criticism is less likely to be expected in a strictly optional
course, but given that the students were in different stages of their PhD training (three students in the second year and one student in the third year), their motivation to participate in this optional course speaks for itself. Indeed, the students’ dedication to attendance despite the pressing demands of their research engagements on time and energy was considered the most valuable indicator of the course’s success. We expect to continue offering the Literature

Table 3. Comments by the participating students on the Literature and Science course

"The course was very motivating for me. Although every book/text that was discussed is rather sad or even frightening in a way it reminds you why you do all these experiments every day. By working only on biochemical levels you sometimes forget the patient behind. The course helped to understand that both (the physiological disorder and the suffering patient) have to be seen to understand the disease. In my opinion this is an important step to optimise appropriate therapies.”

“For me, the course built a bridge between the education during my pharmacy studies and the emotions I experienced towards relatives and friends. While I learned a lot about how to advise patients on diets, regimes and the drugs they take, I never realised, what it really means to them, when they suffer e.g. from Alzheimer’s. Reading these books helped me to become more sensitive and insightful for the treatment of and confrontation with AD patients.”

“The course was a mind-extending opportunity complementing my postgraduate training. The literature was a multifaceted composition that illuminated the different positions and sorrows of patients, family members and caregivers. Both fictional and non-fictional texts were enriching. I became aware that there is no perfect solution to handle AD and that all parties concerned need support beyond the provision of drugs. I think pharmacists are in a good position to sense the patient’s demands and give information on existing additional support.”

“The course offered the opportunity to discuss topics our society much rather excludes from the list of burning issues, i.e., the carer’s personal sacrifice or the patient’s increasing demands, and gave insight into how both patient and carer are ‘afflicted’ by the disease and experience its detrimental impact on their quality of life. The course also gave insight into how patients experience their illness—in contrast to how scientists or doctors view and handle it.”
and Science course and will expand the focus into other neurological conditions, such as Asperger’s syndrome, depression, or Parkinson’s disease. Given the original purpose of the seminar, we believe that the course achieved its intended aims. Indeed, to paraphrase Martin Donohoe, this course contributes to the development of empathic and broad-minded pharmacists, who are mindful of the social and cultural determinants of neurodegenerative disorders (3). Finally, since the core group of students continues to grow steadily, this course may well establish itself as a “fixed” seminar within the departmental PhD curriculum as well as be integrated into undergraduate courses on pharmaceutical care.

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DISCLOSURES

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AUTHOR CONTRIBUTIONS


REFERENCES