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Towards a narrative cardiology: exploring, holding and re-presenting narratives of heart disease

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Is it a pump or is it a pearl?
Is it a muscle or is it a whale?
Is that a scar or is it a medal?

Heart symbolism goes beyond religious iconography and pop culture; it is imbued with experiential significance. But how to reconcile stories of heart disease and patients' perceptions of their hearts with the more technical, anatomical and physiological dimensions of the organ? And why? These were the two fundamental questions underpinning a recent workshop exploring the possibility of a "narrative cardiology" (a tentative definition of a research and teaching area, itself explored during the event), which could help us find answers to these questions. The meeting (*Figure 1*) was held in Bristol at the Chocolate Factory, a creative space including artist studios in the city centre, and organised by the Bristol Heart Institute (GB) in collaboration with the Department of English (MV) of the University of Bristol with the support of the British Heart Foundation and under the auspices of the Centre for Health Humanities and Science (<http://www.bristol.ac.uk/arts/research/centres/health-humanities-science/>).

The workshop comprised a series of talks—addressing the experiential, philosophical, narrative, psychological, artistic, and medical dimensions of the topic—as well as hands-on activities. It was attended by thirty people from different academic or professional backgrounds, purposely incorporating a variety of voices and perspectives in this

reflection, and giving them the possibility of exploring and engaging with *The Heart of the Matter* exhibition (www.insidetheheart.org) in the same venue. *The Heart of the Matter* is a public engagement project and an arts-and-science collaboration rooted in a participatory creative process, culminating in an art exhibition touring the United Kingdom in 2018.

The hands-on activities provided participants with a taster of narrative medicine training, tailored to the needs of contemporary cardiology. In small groups, facilitated by literature and medicine specialists (MV and Dr. Andrew Blades, University of Bristol), participants were invited to analyse poems on heart conditions by award-winning author Margaret Atwood and cardiologist-poet Joseph Gascho, to reflect on similarities and differences between patients' and professionals' perspectives, and to translate this attention to communication issues into practical suggestions for more effective clinical encounters. The perspective of the self was also taken into account, as participants had the opportunity to create a brief story about their own hearts during an embossing workshop (led by co-author artist SL), whereby participants were invited to incorporate imagery relating to themselves on an aluminium plate around a velvet stylised heart (*Figure 2*).

As summed up in a final reflection led by a cardiologist (CBD), the multifaceted nature of the meeting reflected well the multifaceted nature of the heart, with several



Figure 1 The workshop setting included presentations from speakers of different backgrounds, group discussions and text analyses. Images by Stephen King.

clinical references. From Takotsubo cardiomyopathy with its emotional triggers to the long-life nature of congenital heart disease, from the idea of paediatric patients transitioning into adult care to the transformative nature of heart transplantation, patient experience and patients' perception of their hearts cannot be separated from the concepts of anatomy, function, disease, and care, and their underpinning narrative structures.

Engagement with people's stories is, and always has been, at the core of what psychologists do, whatever their professional role or therapeutic approach, and it is no surprise that the burgeoning field of narrative medicine resonates strongly with psychological practice. Moreover, as the field of narrative medicine is in its ascendancy so too



Figure 2 The embossing activity, facilitated by artist Sofie Layton, allowed for further group conversations and facilitated the inclusion of a reflective activity in the context of the workshop. Images by Stephen King.

is the recognition of the importance of patient experience and the need for patient-centred care to be at the very heart of health-care delivery, extending also to paediatrics, and an important element of being able to deliver this involves listening to patients' and families' stories. Children's worlds abound with stories from their very earliest age and they take on an important role in providing familiarity and safety, a way to learn and experience. For some children with heart disease, their whole life may be defined by their condition and its treatment, the requirement for invasive and often painful procedures, the need to interact with strangers in unfamiliar and sometimes frightening medical environments. More so than in adult care, the relationship

between paediatric patients and clinicians is asymmetrical in both knowledge and power, but telling and listening to stories can help to reduce this imbalance. A narrative approach can include not only text but also the use of drawings and photos, making it particularly useful for facilitating communication with children, especially in the context of some of the more 'difficult' topics—as it is often the case in paediatric heart disease. One anecdotal example (shared by J Wray) of the power of narrative cardiology involved a young girl with end-stage heart disease who drew a picture of a princess in a tower, explaining that the princess could not get out of the tower and there would be no prince to rescue her. A cloud passing overhead was raining over her. This girl was dying and what she communicated through her story-telling was her awareness of that, even though she could not directly articulate it. Through careful listening, and empathically interpreting her story-telling, her feelings and fears about her imminent death and her anxieties about the feelings of others (the cloud and raindrops) could be explored using her story. Engaging in the process of listening to her story enabled her needs to be put at the centre of her care and her death to be well-managed.

With growing awareness that our somatic organs carry enormous cultural, historical, philosophical and psychological meaning, bodily organs and functions are now beginning to receive the treatment they deserve from arts and humanities scholars. Of these, the heart seems a prime candidate for such an analysis. Philosopher Jean-Luc Nancy has written of his experience of a heart transplant in his luminous short text, 'L'Intrus' (<http://www.maxvanmanen.com/files/2014/10/Nancy-LIntrus.pdf>). In the text Nancy reflects on his experience of having an ailing heart replaced by another, and notes that this experience is one of intrusion, of being 'sewn open', of continuous exposure to medical surveillance and intervention which is required by a major organ transplantation. The intrusiveness of opening up a body and then manipulating and sometimes removing and replacing one of its organs cannot be underestimated. It is a profound and life-changing experience. HC explained how Nancy's text invites us to reflect on what it is that happens when we open ourselves to such a procedure; as he says, one is never the same afterwards. The myth of recovery, of healing and 'moving on' is exposed as untenable by Nancy's text. One can imagine that a recovery would mean 'going back to how things were'. Whereas in fact, recovery means slowly re-assembling, or re-writing one's life story with the illness in it. There is no complete closure

possible. In a sense, medicine's role is to help those who are ill to find a way to live with, past, or in the shadow of illness. But never to erase its events. A narrative cardiology could be part of this effort to draw attention to the break, the fissure, the trauma, caused by illness, and to the ways of continuing beyond it—be that in rehabilitation, recuperation, regaining of past habits. Engaging in narrative cardiology requires us to acknowledge that such recuperation always contains the memory, traces and scars—both somatic and mental—of the medical events of illness.

Accounts of illness can take different guises—autobiographical, biographical or fictional—but also be told in different manners, from an oral narrative to a poem, from a memoir to a more structured interview. An important dimension of cardiac illnesses concerns the voice in which accounts are narrated: are they offered apologetically and self-effacingly or self-confidently and in apparent certainty? Is a description of what's the matter whispered or enunciated in formulaic conformity with textbook accounts? The depth, tone and figurative depth of a description can wander far from the path of orthodox textbook descriptions: 'A heart attack feels like this', writes Lance Morrow, speaking in a memoir deceptively simply called *Heart* (1). '*A sickness suddenly surrounds the lungs, a sort of toxic interior glow—fleeting at first, lightly slithering, but returning a moment later, more insistent. Not the crush this time, but an alien something... Something dangerous has come inside and will not leave. It clings to ribs and lungs and surrounds the heart like tentacles of green gas. Something wrong, close in... a serpent something in the dark. And sweat shoots from forehead and coats palms... Body walks around, walks around quickly, to and fro, evaluating and denying—sweats and panics, calms, panics again. It will pass.*' But actually it doesn't, and accounts—as here—may (or may not) smoothly or discontinuously align anxiety, suspense, diagnosis and outcome.

Alongside narrative, psychological and philosophical dimensions, there are creative ways to further articulate this. It is interesting to consider the processes of exploring, translating and distilling peoples' lived experiences in other ways. An artist working in a clinical context would see the cardiac narratives emerge at the bedside or through creative workshops. All are individually unique and yet often share common threads. The patient or, within a paediatric setting, the parent have a very specific perspective. The wonder and majesty of the inner workings of the heart take on a totally different narrative dimension when someone has a faulty heart. Now the heart is no longer something other, a set of medical text book terms, but could become

amazing metaphorical forms filled with jelly fish and sea kelp or perhaps a sweet red strawberry. Even the colour of blood becomes inspirational, as discussed by SL in the context of working with a young patient supported by a bi-ventricular assist device. The subtleties of the tones of the colour of oxygenated and deoxygenated blood are not just illustrations, blue and red lines into and out of the heart. The colours are nuanced shades of purple, deep blue and cadmium red and are at the very core of his existence. A 6-year-old boy becomes medicalised during his 7-month-long hospitalisation awaiting his heart transplant. He has learnt to say “ventricular assist device”. However, when asked to describe what his new transplanted heart is like post transplantation, he says “It’s red and it pumps”. It’s bright, alive. So, the artist can also guide patients in exploring elements of their stories, beautiful imagery relating to the form or the implications of disease. The artist can create a space and seek permission to explore these fragile moments in a different way, where poetic concepts that are firmly rooted in medical reality become the inspiration for new artworks which hold and represent these amazing stories.

From the perspective of the healthcare professional, whilst medical knowledge enables cardiologists to understand patients’ signs and symptoms, it is their narrative, feelings and emotions, their metaphors and symbols that can also be revealing about each individual person, supporting any final diagnosis. These contingencies are what make each patient unique despite similar underlying conditions, and what makes a patient-doctor relationship in the best cases uniquely empathic. The heart holds a special place in people’s imagination but also in science. The heart is one of the first organs to form in the early days of intrauterine life, it soon starts beating, giving a rhythm to a new life, and reminding us throughout life that we are alive. It is indeed the flux of life, with blood relentlessly circulating from one chamber to the other and to the rest of the body. The heart is the epitome of life but also death, when inexorably it stops beating, confirming that we lost the patient. It is the ultimate example of the dichotomy of life. As remarked by CBD, a narrative approach from the perspective of a cardiologist thus has multiple facets: the narrative of patients as heard by doctors in clinical encounters occupies a special role, but cardiologists also have a narrative of their own, stories of doctors as healers faced with suffering they wish they could cure or alleviate, the narrative of doctors as human beings impacted by the suffering and the stories of patients, and the narrative of doctors as patients themselves. These aspects

coexist but, depending on the individual circumstances, one can prevail over the others.

As this circle is forming, the patient is sitting at its centre. Narratives around transplantation or congenital heart disease are multifaceted and deeply complex. Interdisciplinary collaborative workshops and discussions involving people from all aspects of the medical journey, coming together, could facilitate the appreciation of different insights, not only in isolation but also in relation to one another, approaching delicate subjects, such as the psychological ramifications of heart surgery in general. For a patient, it can be difficult to share experiences and feelings around surgery and recovery and be fully understood, as there are few that can truly relate to their perspective. Involving patients in these conversations implies creating safe spaces for people to share, without being judged, in a group with the expertise to potentially help shed light on some of those areas (medical and/or experiential). Sharing experiences is a vital part of education and essential in order to develop a holistic narrative surrounding cardiology. What also emerged is the breath of perceptions, from concept of intrusiveness in the discussion surrounding transplant to the positive outlook of young patients with congenital heart disease transitioning into adulthood.

There could even be other dimensions to this multi-layered dialogue. Technology, for instance, offers new ways to reflect on the heart and to present patients with new insights into their hearts. From 3D printing technology to the most exquisite medical imaging approaches to virtual reality, technology is not only integral to cardiovascular research and medical care, but can also represent a prompt for new conversations.

In a narrative framework, listening and honouring stories of illness is advocated to fortify clinical practice. Implementing such a framework, or promoting initiatives to explore stories of heart disease and the interdisciplinary links subtended underneath such stories, could lead medical professionals to that small but fundamental shift that has been beautifully described as the “Cézanne shift” – when repositioning the easel a few inches in a different direction results in seeing, and hence reproducing on the canvas, an entirely different mountain (2).

In the context of the workshop that was piloted in Bristol, this not only involved focusing on concepts of listening to someone else’s story and appreciating the layering of different meanings and the usefulness of (need for?) an interdisciplinary approach at different stages of the process, from creating safe spaces for stories to be

shared to interpretation and representation, but it also involved all participants being reminded of the dimensions of the 'self', where the story is our own, where we can be reflective, maybe playful, but also vulnerable. During the poetry readings, for example, we discussed Atwood's poetic duo "The Woman Who Could Not Live with Her Faulty Heart" and "The Woman Makes Peace with Her Faulty Heart" (originally published in her 1978 collection *Two-Headed Poems*), which illustrates different stages in patients' acceptance of a cardiac diagnosis (3). The woman at the centre of the two poems has to discard the romanticized symbolism of the heart ("a candy shape to decorate cakes with") to look after her irregularly beating "lump of muscle" ("a constant pestering/in my ears, a caught moth, limping drum/a child's fist beating/itself against the bedsprings"). The internal fight is vividly depicted ("the rage as you threw yourself against my ribs"), but the second poem ends on a conciliatory, even if contemptuous, note ("it's an uneasy truce/and honor between criminals"). These feelings can emerge in any consultation; analysing these poems in a formative environment provides healthcare professionals with the narrative tools to acknowledge and address these concerns in their practice for a more holistic approach to treatment. Moreover, Gascho's poem "61M, Systolic Click, BAV" invites a more rounded discussion of the affective dimension of the clinical encounter, which includes the doctor's vulnerability, too ("Some facts I wish I didn't know, like you"). The presence of a scan next to the poem is a powerful reminder of how medical imagining can give rise to multi-layered interpretations ("She will not know just what you want to know") that need to find their place in the clinical context.

These initial reflections on the many narratives at play in a cardiology unit can be further corroborated by rethinking the taxonomies of illness narratives for cardiac patients (4,5). How many of them will perceive the course of their condition as a journey or a rebirth? Does congenital heart disease give a new meaning to the experience of illness as quest? What are the challenges that acute heart failure poses to narratives of medical intervention as restitution? Close reading, "the signature method of narrative medicine" (6), will help health professionals address these questions. Within the time constraints of the workshop, we provided a "flash training" in close reading, but these brief discussions were nonetheless rich, nuanced, and thought-provoking. It was clear how, by paying attention to the rhetorical devices and rhythm of the poems, the participants slowly enacted different principles of narrative

medicine: inclusivity, tolerance of ambiguity, dismantling of hierarchies, and intersubjective approaches were all talked through in relation to the texts and to their clinical practice.

Ultimately, we see this as an opportunity for cross-fertilisation, a moment of inspiration, and also the possibility for identifying new research questions and looking at the value of truly interdisciplinary research.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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