

# Care in healthcare

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## Abstract

In this paper the author argues that an undue emphasis on understanding healthcare in terms of what it does – the activities of care – limits appreciation of what those activities make, or fail to make, in people's lives. As a result, clinicians and healthcare organizations have very little grasp of how human lives are reconfigured through their interaction with healthcare, and the harms that these reconfigurations often introduce. In order to look for another way of understanding the contribution of care in human life and living in terms other than activities of care, the author turns to an ancient account of care. This myth discusses care in terms of its contribution to how human beings have life and are held in life.

## Keywords

Care; Medicine; Healthcare; Myth of Care; Ecology of Care

## Care, competent doing

There is a heavy emphasis in discussions of contemporary healthcare, at least in the United States context where I write from, on the *doing* of healthcare. Healthcare is done in many ways; care is provided, patients are engaged, decision making is shared, evidence is applied, medicines are prescribed, guidelines are issued and followed, measurements are taken, outcomes are sought, imaging technologies are used, records are kept, patient preferences are elicited, medicines are adhered to or not adhered to, risks are communicated, bad news is broken, wishes are respected, patients are put at the center.

Behind the emphasis on doing is a very sensible idea, that if all the things that healthcare needs to do are done well, i.e. competently, respectfully and kindly, then care will follow. Of the three listed above, competence currently subsumes respect and kindness. We instruct our young clinicians to master respect and kindness as a competency in their training, so that they can do respect and kindness when the time comes. In so doing, the very sensible idea becomes a notion that care arises from competency, or, care is competent doing.

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Yet something is amiss in the idea of care as competent doing. Patients and families may be, and often are, competently treated – inter-personally, in communication, scheduling, surgeries, hospital stays, prescription of medicines, etc. These patients will commonly report that they are satisfied with their care, and will rate their experience of care highly. When they leave the enclave of the clinic, however, what was done to them, with them, and for them too frequently fails to work in their lives.



**Figure 1.** Maria-Luisa. (Image credit: Ana Castañeda Guarderas)

This is an image of Maria-Luisa (Figure 1). Maria-Luisa is the grandmother of a colleague who works with our research group. She is 87 years old and for most of those years she lived in her native Peru. Currently she lives in Alaska with her son who takes care of her. Maria-Luisa has hypertension and kidney disease. For the last five years she has organized her life around dialysis three times a week. In addition to living in a part of the world that doesn't speak Spanish, or offer Peruvian food, Maria-Luisa has been told by her doctors that she must follow a diet that is low in sodium, potassium, phosphorous, protein and water. Sometimes when she doesn't follow this advice, she finds herself in the emergency department.

A remarkable set of competencies has allowed Maria-Luisa to be in this situation. In earlier times, she likely would not have lived to be 87 years old. While the achievements of medicine may be remarkable, other, often invisible, aspects of medicine's competent doing manifest here – in a home full of medicine in which she is alive but not happy. Her healthcare has no, or very little, appreciation of this. It is not just that healthcare hasn't looked to see what her life and living looks like, it's also that healthcare often fails to recognize that Maria-Luisa's current way of life is in large part the product of its competencies.

**I wish to argue that in complement to the necessary continued development of competency in medicine, that appreciation and understanding of what is made by the competent practitioners of care also develop.** This requires, in part, a way of understanding medicine in terms of what it

makes, or produces, rather than in terms of what it's doing. The limited facility within contemporary healthcare with a language of care as *made* real in people's lives is perhaps best demonstrated by the prevalence of the term "outcome". Outcome or outcomes is the dominant term used to indicate the end result of all the doing of healthcare, whether that be the doing of a surgeon or the doing of a new drug. Outcome is a term that allows a doctor to review all the medications before Maria-Luisa and say, given the outcomes that we're trying to pursue, these medications are the right ones for Maria-Luisa. The doctor might also go on to say that when Maria-Luisa adheres to her medications, dialysis and diet we see satisfactory outcomes for an 87-year-old woman with kidney disease. Outcome, however, is an inadequate term and idea for beginning to think about what has been made of, and in, Maria-Luisa's life through the competencies of healthcare, yet "outcomes" remains dominant among the very few limited ways currently available to practitioners for accounting for the adequacy and contribution of medical competency in human situations such as Maria-Luisa's.

## The Myth of Care

Living in a time and a culture that pre-eminently values the doing of people and technology, and which typically critiques practice in terms of what practitioners are doing with and to other people, I struggle with finding language appropriate for understanding what healthcare and the decisions of healthcare make in human lives. Rather than attempting to advance a new way of talking appropriate to current circumstance that might help us understand care as it's made in human lives, for the remainder of this paper, I wish to reflect on an ancient account in which competency and the ability to do find their proper relation to what is made. This is done through the theme of care in the form of a myth.

The Myth of Care comes to us from the notes of a young Roman scholar, Hyginus. Its exact origins are unknown but it dates to Greco-Roman times. The myth has two parts:

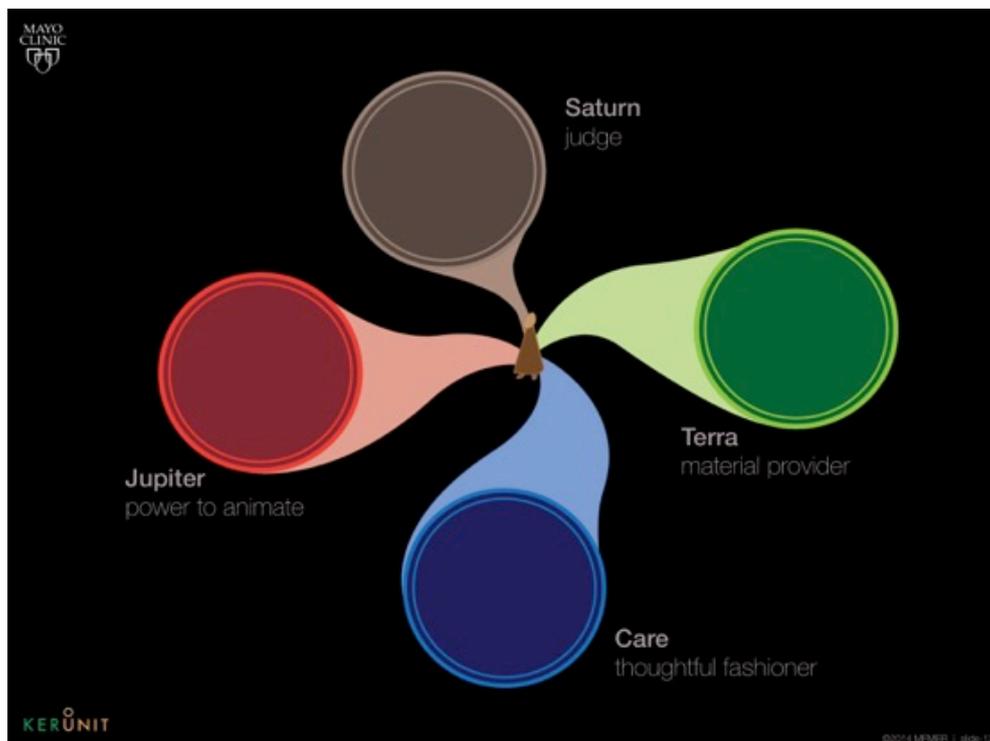
### Part 1

*As Care (Cura) was crossing a river, she thoughtfully picked up some mud and began to fashion a human being. While she was pondering what she had done, Jupiter came along. Care asked him to give the spirit of life to the human being, and Jupiter readily granted this. Care wanted to name the human after herself, but Jupiter insisted that his name should be given to the human instead. While Care and Jupiter were arguing, Terra (Earth) arose and said that the human being should be named after her, since she had given her own body. Finally, all three disputants accepted Saturn as judge.*

## Part 2

*Saturn decided that Jupiter, who gave spirit to the human, would take back its soul after death; and since Terra had offered her body to the human, she should receive it back after death. But, said Saturn, “Since Care first fashioned the human being, let her have and hold it as long as it lives.” Finally, Jupiter said, “Let it be called homo, since it seems to be made from humus (Latin for earth)”.*<sup>2</sup>

It is striking that this myth does not begin by locating care in healthcare, nor in interpersonal relations – two commonplaces of care today. Rather, Care enters as a thoughtful fashioner – one with the capacity to make. Care’s competency in making is not alone; other gods or experts soon join. By the end of the first part of the myth four gods each make claims on the human being, and those claims are based on what each has given out of their particular competencies (see Figure 2.). These gods remain with us today in healthcare; each has a valuable contribution to make, but each faces conflict in its capacity to contribute.



**Figure 2.** The Myth of Care: The four gods.

Terra, the provider of materials, is present in the vast array of materials that clinicians must develop competency in working with. Materials are chemical, biological, psychological, linguistic, social and environmental, to name but a few. One of the most

<sup>2</sup> Reich, Warren T. “The History of the Notion of Care.” In *Encyclopedia of Bioethics*, edited by Warren T. Reich. New York, London: Macmillan Pub. Co. Simon & Schuster Macmillan; Prentice Hall International, 1995.

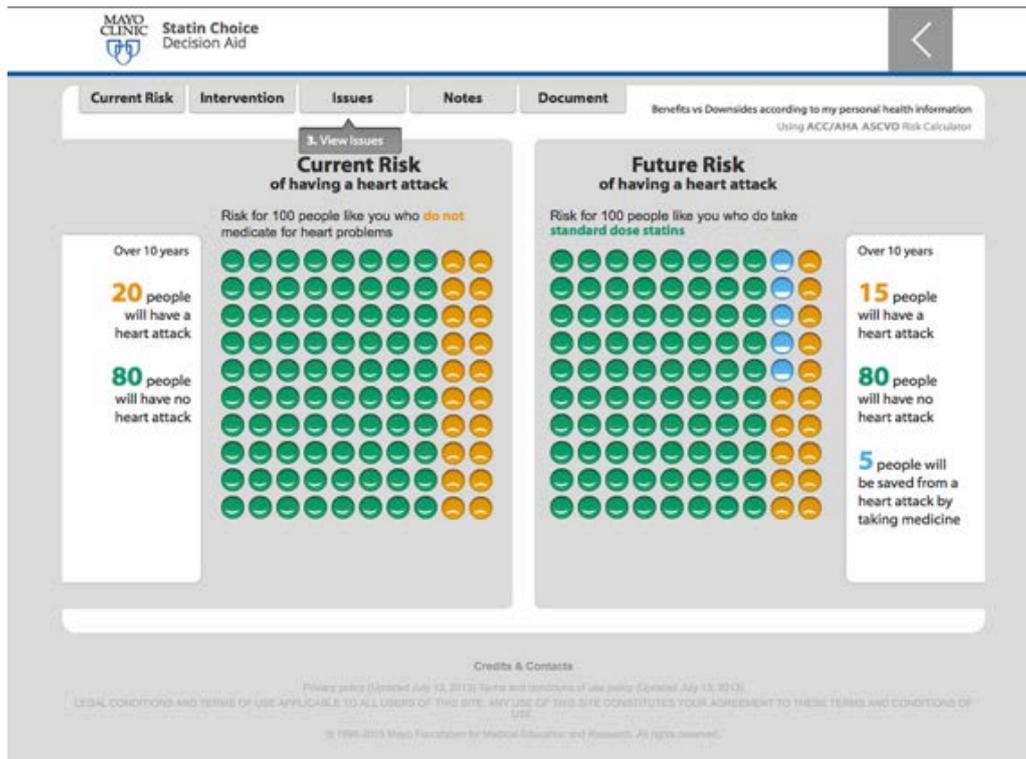
dominant materials in contemporary healthcare are the intellectual materials that clinicians must work with – data, information, evidence. Healthcare is challenged not by a dearth of intellectual materials but with the problem of what to make of the material it has. The vast majority of the research produced by biomedical sciences is neither useful nor usable in contributing to care. Even research that may be potentially useful is often not refined into a form that patients and clinicians can make something of. Beyond this well-produced evidence suffers another problem – evidence alone does not care. Each of the many medications and devices present in the image of Maria-Luisa are there as a result of an evidence-based guideline, each of which is the product of multiple randomized control trials. Yet, the fact that the intellectual material behind the prescription of these drugs – evidence – was of high quality does not help us understand what contribution the medications are making or failing to make in Maria-Luisa's life.

Jupiter, with his power to animate, has always been a part of the care of the ill. He is the god that brings warmth, cheer, humour and hope to enliven the afflicted. The spirited Jupiter is challenged in healthcare in a number of ways. A history of paternalism has distanced doctors from those that they care for. The speech of medicine can often alienate rather than animate patients and their loved ones. Clinician burnout fuelled by demanding working conditions and expectations is a growing problem, sapping the spirit from clinicians who spent year upon year to be in a position to care for people. At the same time clinicians are directed to “engage” their patients with little direction as to what this engagement is. Jupiter is also at play from the patient side. Patients are encouraged to be empowered and let their voices be heard rather than acquiescing to whatever the doctor directs. Yet when patients seek to animate care through their voice, healthcare and family members often do not know how to make something of it. Recently I spoke with a critical care doctor who said that 90% of advanced directives – written expressions of what a person wants when they are very ill and can't speak for themselves – are practically useless for the situations that patients and their families are in when they're in an intensive care unit.

Saturn, the judge, is very much present today also. He is present in the many judgments by which care proceeds. A lot of my work as a designer involves creating tools to help patients and clinicians together decide on what to do – in a process called shared decision making. This decision aid (see Figure 3), for example, is intended to help in deciding whether or not to begin a class of medications called statins to reduce the risk of heart attack. While these decisions can be important, at other times they do not matter at all. I recall a haunting story told by Dr Iona Heath from the United Kingdom<sup>3</sup> of a newly trained colleague eager to share his new understanding of statins with his patient – a woman in her early seventies. After explaining the ins and outs of the medication and asking her what she thought, the woman turned to her doctor and after a lengthy silence said “But, John is dead and the boys have moved away”. What the doctor was trying to decide on was not at all the situation that mattered for this woman.

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<sup>3</sup> Recounted in a keynote address given at the International Conference on Communication in Healthcare in Heidelberg, Germany, in 2016.



**Figure 3.** Shared decision making.

The first part of the myth ends with the competences of the various gods in conflict with one another. In the second half of the myth, conflict resolves when attention is turned to what is being made through the contribution of each god – the human being and a human way of life. In so doing the character of each god is subtly transformed.



**Figure 4.** The Myth of Care: The transformation of the four gods.

In the naming of the human after Humus, there is recognition that the life of the human is in continuity with that of the earth – that there are materials that are properly human during life, and the place of those materials in care is to nourish life. Terra transforms from a giver of material to a contributor in the nourishment of human life and living.

It is Jupiter, not Saturn the judge, who says that the human should be named for Humus. In this act, Jupiter's character shifts from a power to animate according to his will to a generosity of spirit that enables other gods – contributors – to bring forward their best in care for the human being.

Saturn the judge is transformed also from a competency in deciding to a fostering of resolution – of bringing forward a just peace that attends to a troubling situation, such as illness. The goddess Care is transformed too, the significance of her thoughtful fashioning shifts from a competency – a skill in craft, to a responsibility – that of having and holding of the human in life. The object and significance of care moves from formed mud to how human beings have and are held in life.

Through the Myth of Care, it possible to catch a glimpse of care in healthcare, not as many competent doers (the gods from the first part of the myth), but as what those competencies contribute to make in care, Maria-Luisa and her life and living.

## **About the author**

Dr Ian Hargraves is an Assistant Professor of Medicine and Principal Health Services Analyst at the Mayo Clinic, Rochester, Minnesota. His expertise is in design and patient-clinician interaction in shared decision making. Dr Hargraves holds a Bachelor's degree in Industrial Design from Victoria University in Wellington, New Zealand; and a Master's degree in Interaction Design along with a PhD in Design from Carnegie Mellon University, Pittsburgh, Pennsylvania. His doctoral research considered design as care.