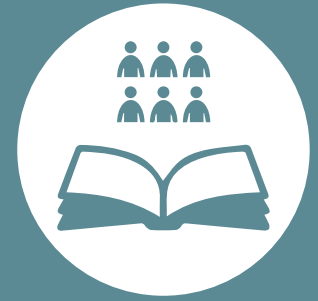


Guillemin, M. (2004). Embodying Heart Disease Through Drawings. *Health*, 8(2): 223–239.



Chapter 7

STRUCTURES AND INSTITUTIONS

In Chapter 7, we discussed the role of social institutions in shaping our behaviour and interactions with others. In this chapter, we focused on the institutions of education, media, family, and work but medicine is also understood by sociologists a key social institution. In much the same way as the institutions we looked at in Chapter 7, the institution of medicine also helps us to behave appropriately in society both by treating disease, and by preventing ill-health in the first place. Similarly to the institutions of family, the media and work, medicine shapes and structures the whole of our lives. Even before we are born, we are already subject to a ‘medical gaze’ through ultrasound scans, pre-natal screening and foetal monitoring (see Roberts 2012). Then even after we die, our bodies might be studied by scientists, or they might be used in medical student education, or parts of them might be transplanted into other patients. And of course, medicine as a social institution is with us throughout the bits in between – from our childhood vaccinations, through contraceptive advice in early adulthood, through our own reproductive health, and on to the health complications that come with older age.

Given how ubiquitous medicine is, sociologists have explored the myriad of ways that people interact and engage with medicine throughout their lives. Some of this has been highly critical and argued that medicine works as an institution of ‘social control’ (Zola 1972) where every part of everyday life has become subject to a high level of medical intervention. This is a process called ‘medicalization’ where ways of behaving that we once considered *socially* problematic or questionable, have slowly become understood to be *medically* problematic and, therefore, in need of medical monitoring and treatment. Let’s go back to our example of reproductive health – pregnancy is a good example of medicalization. Until the early decades of the twentieth century in the West, pregnancy was understood as a natural social phenomenon that was managed by midwives and lay practitioners, rather than by doctors. But over the twentieth century, pregnancy became defined as ‘medically problematic’ and subject to all kinds of monitoring and interventions such as ultrasound scans, pre-natal screening, and antenatal classes (Barker 1998: 1067). While these technologies are branded as supporting foetal health, sociologists have suggested that such intense medical monitoring during pregnancy can be distressing, invasive and risky (see Thomas et al. 2017). David Armstrong (1995) calls this kind

of medical monitoring ‘surveillance medicine’. This term refers to completely normal, unproblematic bodily states (such as a pregnancy with no complications) becoming subject to constant medical monitoring.

But not all medical sociology focuses critically on the institution of medicine itself. A huge amount of medical sociology is focused on people’s lived experiences of health, medicine, and illness. In other words, what is it like to live with a particular disease or condition? That’s what Marilys Guillemin (2004) wanted to find out in the specific case of heart disease and so she recruited 32 women who’d been diagnosed with heart disease to understand how her participants understood their condition. While she started off by interviewing her participants (see Chapter 8’s blog), Guillemin followed these interviews by asking participants to *draw* ‘how they visualized their condition’ (page 224) and then to narrate their drawing process – why they’d used specific colours, and why they’d structured/arranged the drawing as they had. By asking participants to explain their drawings, Guillemin was able to use drawings as both data items themselves but also as ‘processes’ through which her participants were able to develop an embodied knowledge of their condition.

Drawing methods (or arts-based methods more generally) are highly creative approaches to engaging with participants in sociology. These methods aren’t always just about participants creating art but can also involve researchers composing drawings, paintings, or even music alongside participants which can break down barriers and increase rapport and trust between researchers and participants. This type of approach involves ‘conducting research *with* participants rather than on them’ which can be particularly helpful for participants who are vulnerable in some way (Coemans and Hannes 2017: 40). Arts-based methods are also useful for gathering data about sensitive topics. O’Neill (2011), for example, used arts-based methods in her research with forced migrants to help participants tell their stories and untangle the complexities of identity, place, and belonging.

For Guillemin (2004), arts-based methods allowed her to talk with participants about their heart disease in a different way from her interviews alone, and to elicit stories which may not have been shared through other qualitative methods. By visually representing their understandings of heart disease, Guillemin’s participants were able to give ‘a different kind of insight’ (page 234) into the experience of living with heart disease and to tell stories which they may not have shared in interviews. For example, several of Guillemin’s participants drew hearts that depicted their medical history which, although clearly relevant for participants’ understandings of their condition, may not have emerged in interview narrowly focused on current heart disease experiences.

But more fundamentally, arts-based methods allow researchers to access participants’ internal thoughts, processes and visualisations which are rarely made public in sociological research. So while participants might be asked, in interviews for example, to discuss their experience of heart disease, how their daily life is affected, and how they construct a positive identity as a person with heart disease, Guillemin asks a more basic but no less important question – how do participants visualise and understand their condition? Through drawing these visualisations, Guillemin was able to access participants’ innermost thoughts about their own hearts

and bodies. Participants depicted their hearts as disembodied (i.e. not attached to their wider body) symbols at the centre of their drawings, which Guillemin understood as a result of the simplified, lay discourse of *heart* disease, rather than the biomedical definition of *cardiovascular* disease. Other participants depicted their hearts within their wider body but having to work incredibly hard which Guillemin interpreted as representing ‘the emotional and physical impact on women’s lived bodies’ (page 231). In both cases, these understandings of the heart would most probably not have emerged during interviews.

One challenge for researchers, though, is knowing how to analyse the drawings that have been produced by participants. While researchers can use thematic visual coding approaches, where they look for commonalities and differences across participants’ drawings, there is a risk that researchers’ interpretations may not match up with what participants were trying to represent. In addition, by looking across a whole dataset, researchers might miss the nuance and complexity of individual stories and art works. Guillemin addressed this by focusing on the *process* of making drawings and asking participants to talk through their drawing design.

Another challenge for researchers is that, in short, asking participants to draw things is a bit strange! For Guillemin’s participants being asked to draw their visualisations of heart disease ‘often seemed to come as a surprise’ (page 226). In van der Vaart et al.’s (2018) study of a changing rural Dutch village, they experienced some ‘drop off’ in participant numbers as their research moved from convention to more arts-based methods. And this strangeness doesn’t just impact on data collection and the research process itself. Drawings and other arts-based data are difficult for researchers to share in fairly staid academic formats, especially journal articles. So while Guillemin gave her participants 12 different coloured felt pens and talked about her participants’ use of blue to represent blood, pink to represent optimism, purple to represent healing and green to represent new life, the drawings in her article are black and white.

QUESTIONS:

1. Think of an everyday, taken for granted concept, object, or phenomenon (like your heart, family, nature, love, home) and ask a friend or family member to draw how they imagine this concept. How did they react? Did they represent that subject in a different way from how they might have done if you’d interviewed them?
2. If academic journals aren’t the ideal place for sharing arts-based data, where should sociologists publish their visual data?
3. Was drawing a good way for Guillemin to elicit participants’ stories about their health condition?

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