RECONSIDERING PATIENT CENTRED CARE

Between Autonomy and Abandonment

ALISON PILNICK

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Reconsidering Patient Centred Care: Between Autonomy and Abandonment

ALISON PILNICK
University of Nottingham, UK

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For my parents, Irene and Mike, who – amongst so many other things –
took me to the library.

List of Abbreviations

CA	Conversation analysis
ESRC	Economic and Social Research Council
HCP	Healthcare professional
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
PCC	Patient centred care
PCM	Patient centred medicine
PLWD	People living with dementia
WMO	World Medical Association
WHO	World Health Organisation

About the Author

Alison Pilnick is Professor of Language, Medicine and Society in the School of Sociology and Social Policy. She has been researching communication in healthcare for over 25 years, with the aim of improving the experiences of patients and developing and informing training programmes for healthcare professionals. This research has been funded by bodies including ESRC, NIHR, UK Department of Health, The British Academy, the Swiss National Science Foundation and the General Research Fund of Hong Kong. All of Alison's work is underpinned by a broader desire to use sociological expertise to improve healthcare policy and practice. She was elected a Fellow of the Academy of Social Sciences in 2015 in recognition of her work in this area.

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My experiences of the COVID-19 pandemic are those which are shared with many people, including the emotional impact of personal loss and the practical impact of prolonged homeschooling. I am therefore grateful for the understanding of colleagues at Emerald, initially Jen McCall and latterly Kimberley Chadwick, who have patiently adjusted deadlines and rejigged production schedules in response. I hope that my family are glad to see me finally emerge from the spare room with the finished manuscript, and thank them for their ongoing love and support.

Introduction

This chapter will introduce the aims and scope of the book and set the scene for the following chapters. It will also outline the way the terms patient centred care and person centred care are used in key NHS policy documents and service standards. The distinction between these two terms and the varying ways in which they are used will also be considered briefly, with an explanation of the way this, and other terminology, will be used in this book. Finally, I will present a brief overview of the contents of each of the five chapters.

The NHS constitution (Department of Health and Social Care, 2021), updated every 10 years, is the document which establishes the principles and values of the NHS in England. As part of this it sets out the rights to which patients, public and staff are entitled in relation to its operation and service delivery, as well as pledges which it is committed to achieve. The document is organised around seven key principles: one of these is that 'The patient will be at the heart of everything we do' (NHS, 2021, Principle 4). Whilst this principle is expanded on as follows: 'NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers', the terms patient centred or person centred care are not used in this document. Despite this, other NHS policy documents present patient or person centred care as the means of achieving this principle in practice. The importance attached to the principle can be seen by the way it recurs in both NHS England policy for service delivery, and in Health Education England policy for workforce training and development. Health Education England states that 'being person-centred is about focusing care on the needs of the individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them' (see e.g. https://www.hee.nhs.uk/our-work/person-centred-care); as a result there is a stated need to develop a workforce with behaviours, skills and competencies that support and drive these person-centred approaches. Patient or person centred care is also described as the way to ensure 'the needs of the patient are central to the development of new care models', for example in integrated care (www.england.nhs.uk/integrated-care-pioneer/resources/patient-care). In order to turn this aim into a reality, NHS England has a dedicated person centred care team. As part of the drive towards a 'truly person centred NHS', this team produce guidance to staff across NHS England to 'make sure that person centred care is core in all our work' (www.england.nhs.uk/ourwork/patient-participation).

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The extent to which these principles underpin contemporary healthcare practice in England is clear, though their pervasiveness is certainly not limited to an English or a UK context (see for example the federally funded US Patient Centered Outcomes Research Institute: https://www.pcori.org/). However, as the wording of the documents quoted above show, they are commonly invoked at a level of abstract generality. What is also clear from the wording is that, in the abstract, they are largely regarded as an uncontentious force for good, acting to curb the traditional imbalance of power in the practitioner/patient relationship. In this sense the current landscape can be seen as the logical policy end point of efforts to reform the practice of medicine which began in the 1960s, aimed at addressing the occurrence of medical dominance over, or even oppression of patients (Pilnick & Dingwall, 2011). From this perspective, it is perhaps surprising that both a 2001 Cochrane systematic review of interventions aimed specifically at increasing patient centredness in consultations, and a 2012 update of this review (Dwamena et al., 2012; Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001) found a mixed picture. While such interventions are generally successful in modifying styles of communication and sometimes succeed in increasing rates of patient satisfaction, it is much less clear as to whether they result in positive health outcomes.

These findings beg the question of how a policy that seems on the face of it morally incontrovertible can fail to work in practice. I will argue throughout this book that understanding this failure requires an understanding of the way in which healthcare interactions work in practice. Whilst healthcare policy initiatives generally originate in a top-down way as a result of moral or organisational imperatives, their actual implementation often depends on them being talked into being by healthcare professionals as they interact with their patients or clients. It follows that judging the success or otherwise of these initiatives ultimately depends on examining actual interaction between patients and professionals. While it is increasingly common to consider professional-patient interaction as an evaluative tool, a central contention of this book is that it is also the means by which we can understand not just *what* happens in healthcare delivery, but also *why* it happens. The detailed analysis of healthcare interactions involving a variety of professionals and from a wide range of contexts can help us understand why attempts to deliver patient centred care have not had the impact on healthcare that might have been expected. As I will argue, the logical consequence of this is that an understanding of interaction needs to be better embedded in healthcare policy making from the outset.

There are important two notes on terminology to make here. The first is on the distinction between patient centred medicine (PCM), patient centred care (PCC) and person centred care. In general terms, PCM is often used in a broad sense, to denote a shift in the way the field of medicine is conceptualised. Patient centred care is then often (but not exclusively) used to describe individual consultations or actions within this field. The terms patient centred care and person centred care are sometimes used interchangeably in the literature, with usage of the latter term becoming much more common over the last 10 years. As has been the case for descriptions of NHS policy, in some contexts more recent iterations of service descriptors and frameworks have therefore substituted 'person' for 'patient' without any broader change. However, the term 'person centred' has different origins and is also sometimes used in a more ideological sense, signalling a wider aim of demedicalisation and a focus on the person beyond their role as a patient. This distinction and the ideology behind it will be discussed further in Chapter 1. In order to acknowledge the presence of the distinction as drawn by some commentators, I will use the terms separately here. In keeping with the majority of the literature that I will draw on, and as the title of the book suggests, I will generally use the term patient centred care. I will reserve the use of the term person centred for discussing research or commentary which seeks to highlight the proposed distinctions.

The second note relates to the fact that almost all early research in this field focuses on doctors and patients, reflecting the way doctors, and in particular primary care physicians, were historically often seen as the primary site of healthcare delivery. To some extent this focus is still reflected in current research, and so when reporting on research that has used the terms doctor and patient, they will be reproduced here. However, that does not mean the wider arguments I will make are limited to this context, and the empirical examples I will draw on include a wide range of healthcare professionals practicing in a variety of settings. Additionally, as the remit of health services have developed and widened, ever growing numbers of allied health professionals are now involved in the delivery of healthcare, and for some of these professionals the recipients of their services are generally described as a clients, rather than patients. To some extent this may reflect the philosophy of a service (for example services that align themselves to some degree with a counselling paradigm, such as genetic counselling, tend to use the term client). For other services this can reflect the type of care that is delivered, for example in preventative healthcare services where a person is not currently (and may never become) ill. This book is intended to speak to both patients and clients, and to healthcare professionals beyond the doctors who feature in early research. My own data come from a wide range of healthcare settings, and for practical purposes, when I am referring to these data I will use whatever term the service where the data were collected chose to use.

The remainder of this book is divided into five chapters:

Chapter 1 will trace the history of patient centred care, and explore some of the varying ways in which it has been defined, including its relationship with the concept of Shared Decision-Making. It will move on to show how, despite the fact it is presented as the logical end point of reform to the doctor-patient relationship that has been ongoing since the 1960s, there is little clear evidence for its impact on healthcare. The promotion of PCC therefore rests on a moral position rather than on its outcomes. I will argue that understanding the failure of PCC to produce its expected impact requires a detailed understanding of the way in which healthcare interactions work in practice, which has hitherto been absent from healthcare policy.

Chapter 2 will build on the conclusions of Chapter 1, highlighting that whilst many healthcare policy initiatives originate in a top-down way as a result of moral or organisational imperatives, their implementation often depends on being talked into being by healthcare professionals. I will introduce the analytic approach of Conversation Analysis that is used throughout this book, and show how analysing data from this perspective can begin to help us understand why it is that PCC has not had the positive impact on health outcomes that might have been expected. I will illustrate this argument with examples of the way choice, care and control are negotiated and enacted across a range of healthcare settings. In the second part of this chapter, I will examine the way in which checklist-based conceptions of PCC generally assume that 'good' and 'bad' communication can be identified a priori and acontextually. However, CA analyses show that there can be good organisational reasons for what may on the face of it look like 'bad' healthcare practice, and that practices which are assumed on the basis of everyday interaction to be inclusive, supportive and patient centred may not operate this way in a healthcare context.

Chapter 3 will continue to develop the analysis presented in Chapter 2. However, while Chapter 2 illustrates a variety of ways which might lead to individual 'failure' to enact PCC, rooted in competing organisational imperatives, and 'dysfunctions' (Heritage, 2011) in the transfer of practices from ordinary conversation to healthcare interaction, in this chapter I will argue that there is a more fundamental reason why policies such as PCC are not enacted in practice in the way we might expect. Despite the fact that many healthcare policies have to be talked into being by healthcare staff, policies are not generally grounded in an understanding of how interactions actually work. Drawing again on real-life examples from my data corpus, I will show how some of the policies and practices used in the service of PCC result in interactional conflict because they require healthcare professionals to manage competing interactional norms. This means that, while these policies and practices may make organisational sense, or make moral sense from a particular perspective, they do not make good interactional sense. In other words, there can be good interactional reasons for what may look like 'bad' healthcare practice. I will argue that this problem will not be resolved simply through 'better' training in PCC but instead requires an acknowledgement and understanding of why and how these interactional conflicts arise in healthcare interaction. In part, this is linked to the way the conceptualisation and delivery of PCC can problematise professional expertise.

Chapter 4 will consider the issue of medical expertise in more detail, outlining the changing ways it has been understood sociologically in order to understand how the healthcare professional/patient encounter has come to be viewed as a struggle for control. I will use data from healthcare interactions to show the ways in which medical expertise is collaboratively constructed, and how absolute prioritisation of the 'epistemics of experience' (Heritage, 2013) over this can ultimately lead to patient abandonment or to care which falls short of professional standards. A failure to understand this, because of a failure to understand how healthcare interaction works in practice, means that practices and policies introduced with the intention of empowering patients or improving their care can actually have the opposite effect.

In the final chapter of this book (Chapter 5), I will consider what the consequences of my critique might be for a way forward. I will suggest that the pervasiveness of PCC needs to be understood in the context of its relationship with consumerism, and consider whether it is possible to envisage a reimagining of PCC or whether it is better abandoned altogether. In considering this, I will highlight the problematic way in which social science has been co-opted to serve a sociology *in* medicine rather than a sociology *of* medicine (Straus, 1957), and suggest that a critical sociological engagement allows us to propose alternative possibilities beyond more or 'better' training in PCC. Finally, I will return to a theme that runs through all the chapters of this book: that healthcare policies generally depend on interaction between individuals for their enactment; as with PCC, they have to be 'talked into being'. This means that understanding why policies may not work as intended requires an understanding of human interaction. I will argue that this ultimately points to a need to consider to what extent an understanding of interaction can be used to inform policy making from the outset, rather than simply using it as a tool to measure the success or otherwise of its implementation.

In concluding this introduction, it is important to note here that this book draws on research I have conducted over a 25-year period, funded by a variety of UK and international funders. I have provided more details on these projects in Chapter 2, as well as referencing some of the publications that have arisen from them in support of analysis throughout the book. None of these previous projects focused specifically on patient centred care, but in collecting and analysing these data for other purposes the context of PCC and the impact this has on healthcare interaction has always been present on the periphery. This book represents my attempt to place PCC at the centre of my work and to produce a substantive critical engagement with it.

Chapter 1

What Is Patient Centred Care?

This chapter will begin by tracing the history of patient centred care (PCC), setting this against a backdrop of changing sociological conceptualisations of the doctor/patient relationship. It will highlight the fact that there is no universally accepted definition of PCC, and explore some of the differences in widely used definitions. I will move on to show how a lack of conceptual and definitional clarity have led to difficulties in measuring the success or otherwise of PCC, but that even allowing for this there is no clear picture of its positive impact. The available empirical evidence suggests that, in general terms, adoption of PCC can lead to improved patient satisfaction, but not to improved health outcomes. Despite this, most empirical research into PCC assumes the primary problem is individual or service level failure in its enaction, rather than questioning the principle itself. I will consider how this lack of critical interrogation of the concept is due to the fact that PCC is presented as a moral position, and in this sense can be seen as the logical policy end point of efforts to reform the practice of medicine which began in the 1960s, aimed at addressing the occurrence of medical dominance over, or even oppression of patients (Pilnick & Dingwall, 2011). In the latter part of the chapter I will examine the relationship between PCC and shared decision-making (SDM), and reflect on some of the concepts that underpin both terms, particularly in relation to the prominence given to patient autonomy and individual choice. Finally, I will consider the distinctions that are sometimes made between patient and person centred care, and the ideology that lies behind the choice to use either of these terms. This distinction will be set in the context of a wider critique of the way the ‘vocabularies of the therapeutic’ (Rose, 1999, p. 218) have increasingly found their way into the mainstream. I will conclude by arguing that in order to understand why PCC has not had the impact on health outcomes that might have been expected given its ‘moral rightness’, we need to examine the way healthcare interaction works in practice.

Tracing the History of Patient Centred Care

One of the difficulties of any substantive engagement with patient centred care is that there is no universally accepted definition of the concept. What is generally agreed is that it was first introduced by the psychoanalyst Michael Balint in 1955–1956, as part of his work with UK General Practitioners. However, even at the outset, the concept was largely defined not by what it was but by what it was

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not, described and explicated as a contrast to the reductionist, biological approach of illness centred medicine. Underpinned by the philosophy of holism, Balint's approach instead centred the idea that patients needed to be seen in their biopsychosocial entirety, so that doctors should consider the 'pathology of the whole person' (Balint, 1964/1957, p. 7). As both he and his wife, Enid Balint, noted, they were not always faithful to the specific term, occasionally using the term 'patient-oriented medicine' as an alternative (Balint, 1969; Balint et al., 1969). Whichever term was used, within this approach, and consistent with Balint's psychoanalytic background, relational matters were paramount, since it was 'Not only…the box of pills that mattered, but the way the doctor gave them to his patient' (Balint, 1964/1957, p. 1). Balint urged the practitioners he worked with to consider the importance of listening, particularly when in doubt about how to act, reminding them that they were participants in 'a peculiar, lopsided two person relationship' (1964, p. 252). This lopsided nature, and the strength of the doctor's position relative to the patient's, was grounded in an asymmetry of medical knowledge, allowing the doctor the ability to explain and interpret, in contrast to the patient who came to see the doctor precisely because they could not understand or resolve the problem themselves.

This asymmetrical view of the doctor–patient relationship can be traced back, sociologically speaking, to the work of Talcott Parsons in the 1950s. As a structural-functionalist, Parsons' interest in sickness was grounded in the way it represented, for him, a form of deviance: a sick person was not a productive member of society because they could not fulfil their normal social roles. In order for societies to function, there needed be a recognised mechanism whereby people could be exempted from or returned to their normal roles. For Parsons, the management of illness is therefore a mechanism of social control for a capitalist society. In setting out his model of the sick role (Parsons, 1951), Parsons identifies three significant features of patients in this role: they are helpless; they do not possess the technical abilities to solve their own medical problems; and they are emotionally involved with their own illnesses, so that they cannot be relied upon to act rationally. Indeed, as Armstrong (2014) observes, for Parsons the very nature of patienthood was such that the sick were not competent to help themselves. Though the sick role model absolved patients of the responsibility for their illness through a recognition that they could not avoid or mitigate it themselves, it also presented them with a responsibility to submit to professional help. This help seeking necessarily placed them in a dependent position, with little space for independent action. As subsequent generations of sociologists have argued, the ultimate implication of Parsons' model is the potential that a person becoming a patient also becomes vulnerable and docile, with 'no responsibility for their predicament and minimal involvement in their own care' (Armstrong, 2014, p. 164).

In Parsons' defence, some commentators have argued that over time, and as a result of his focus on the social contract in relation to health, an overly structural version of his work has become popularised (Rawls & Turowetz, 2021). It should also be noted that his conception of physicians' professional power and autonomy encompassed a characterisation of the physician as at all times using their