Repositioning the Patient: Patient Organizations, Consumerism, and Autonomy in Britain during the 1960s and 1970s

ALEX MOLD

SUMMARY: This article explores how and why the patient came to be repositioned as a political actor within British health care during the 1960s and 1970s. Focusing on the role played by patient organizations, it is suggested that the repositioning of the patient needs to be seen in the light of growing demands for greater patient autonomy and the application of consumerist principles to health. Examining the activities of two patient groups—the National Association for the Welfare of Children in Hospital (NAWCH) and the Patients Association (PA)—indicates that while such groups undoubtedly placed more emphasis on individual autonomy, collective concerns did not entirely fall away. The voices of patients, as well as the patient, continued to matter within British health care.

KEYWORDS: consumerism, autonomy, patient organizations, consent, medical education

Over the past thirty years the patient has come to occupy an increasingly central position within British health care. Policy documents from the consultative paper *Patients First* (published in 1979) to 2010's white paper on the future of the National Health Service (NHS), leave the reader in little doubt that the patient is, or should be, "at the heart of everything we do."[1] While it might seem self-evident that the health system should

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1. Department of Health and Social Security, *Patients First* (London: HMSO, 1979); Cm 7881, *Equity and Excellence: Liberating the NHS* (London: TSO, 2010), 1.

be designed in such a way that it benefits patients, the role or roles that patients were expected to perform have changed considerably over time. In the early 1960s, for example, it was not uncommon for patients to be told little about the condition they were suffering from or its likely outcome. Ann Cartwright, in her 1964 survey of human relations and hospital care, found that many British patients complained about a lack of information concerning their illness, its treatment, and the prognosis. One patient told researchers, "I'd like to have known just what was wrong with me, which kidney it was and if I'd be completely cured. Also I wanted to know if I could have any children. They just jump down your throat if you ask them."[2]

That such a situation would be (almost) inconceivable today points not only to changes in the doctor–patient relationship, but also to a wider shift in the way in which patients see themselves and are seen by others. This article explores how and why such a shift took place and assesses the extent to which, by the end of the 1970s, the patient had been repositioned as an autonomous entity within British health care. A range of factors contributed to changes in the role of patients. Emerging medical technologies and the growing power of the pharmaceutical industry helped to reconfigure patients' minds and bodies.[3] But there were also developments that led to patients being viewed as *political actors*, and it is these shifts that this article illuminates. From its foundation in 1948, the NHS provided universal access to health care that was free at the point of use, but the early health service was structured in such a way that there was no real mechanism for hearing the views of patients. Furthermore, a culture of paternalism existed within the medical profession perpetuating the view that "doctor knows best" and patients should accept a largely passive role. Yet there were signs from the early 1960s onward that such views were beginning to be challenged. As the journalist Gerda Cohen remarked in 1964, "[P]atients are becoming impatient: of being treated like chipped flowerpots in for repair; of queues; of being kept in ignorance."[4] At both the individual and collective levels patients were demanding more say in their own treatment and in the management and development of health services. The patient, in both the hospital ward and in the corridors of power, could no longer be ignored.

2. Ann Cartwright, *Human Relations and Hospital Care* (London: Routledge & Kegan Paul, 1964), 75.

3. See, for example, Ayesha Nathoo on heart transplants in *Hearts Exposed: Transplants and the Media in 1960s Britain* (Basingstoke: Palgrave, 2009). For a more recent take on the reconfiguration of the patient by the pharmaceutical industry in a global context, see Adriana Petryna, *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects* (Princeton, N.J.: Princeton University Press, 2009).

4. Gerda L. Cohen, *What's Wrong with Hospitals?* (Harmondsworth: Penguin, 1964), 9.

The changing political role of the patient can be explained in the light of two interrelated developments: first, the growing importance placed on individual patient autonomy; and second, the development of consumerism within health care. During the early 1960s, the notion that patients had the capacity to "reflect and decide" on their treatment, a concept that was to become crucial to later formulations of bioethics, began to gather support.[5] Autonomy, that is, the ability to make decisions about individual care and treatment, was being foregrounded by patient organizations such as the Patients Association (PA). At the same time, autonomy was also central to the idea that patients could be thought of as "consumers" of health care. Interest in consumer "rights" started to attract academic and political attention: even the *Lancet* commented in 1961 that "[e]mphasising the 'consumer point of view' can be very valuable."[6]

Some commentators would suggest that consumerism really began to play a significant role in British health care only in the past twenty or thirty years.[7] The various changes to the health service brought about by Conservative Prime Minister Margaret Thatcher and her successors, such as the introduction of general management, the development of fund-holding general practitioners, and the establishment of the internal market within the NHS, tend to be seen as the beginning of explicitly consumerist developments.[8] This article suggests that consumerism within British health care had deeper roots, and if we look to the activities of patient organizations in the 1960s and 1970s, we can find traces of claims that were to become part of these wider forces. To do so is not to read back anachronistically contemporary notions of consumerism, or to contribute to a Whiggish history of the inevitable "rise" of such developments: instead, this article investigates some of the conditions that made health consumerism possible, pointing particularly to the role played by patient groups in this process.

To explore the ways in which patient organizations began to reposition the patient through emerging notions of health consumerism and patient autonomy in Britain, this article focuses on three areas. First, it attempts to uncover what patients themselves thought of health care in the 1960s and

5. David Reubi, "Ethics Governance, Modernity and Human Beings' Capacity to Reflect and Decide: A Genealogy of Medical Research Ethics in the UK and Singapore" (Ph.D. diss., London School of Economics & Political Science, 2009), 69.

6. Anon., "Patients as Consumers: Wants and Needs," *Lancet*, April 29, 1961, 927–28, quotation on 928.

7. Christine Hogg, *Citizens, Consumers and the NHS: Capturing Voices* (Basingstoke: Palgrave, 2009).

8. Ian Greener, "Towards a History of Choice in UK Health Policy," *Sociol. Health Illness* 31, no. 3 (2009): 309–24.

1970s. This is difficult to do, as the opinions of patients were not collected systematically in this period: indeed, seeking patients' views on the health service was a new development. In a sense, then, this section is as much about views of the patient as it is about the patient's view, as other actors, including sociologists, whistle-blowers, and consumer organizations came increasingly to speak for and about the patient. What these various groups seemed to be saying was that there was something wrong with aspects of the care and services being provided: that the patient should have more of a say in determining what happened to his or her own body, but also in the fate of services as a whole.

The extent to which this call for more autonomy and involvement was taken up by patients themselves can be assessed through the examination of two case studies. The first is offered by the work of the National Association for the Welfare of Children in Hospital (NAWCH) and the organization's attempts to get hospitals to permit the unrestricted visiting of children in hospital. NAWCH provides a particularly pertinent example because the organization worked both with and against the medical profession. The organization challenged current practices but at the same time was always careful not to be seen as too radical. In this way NAWCH occupied a space between the research-focused and doctor-orientated medical charities of the 1940s and 1950s and the more patient-centered organizations that came into being in the 1960s and 1970s.[9] A rather different example to the work of NAWCH is suggested by the activities of the PA and its campaign to establish a right for patients to consent to participate in the teaching of medical students. The PA was more overtly hostile toward the medical profession, and more willing to challenge openly what it saw as bad practices. The PA's work encapsulates neatly the difficulties facing those who attempted to speak for patients in the 1960s and 1970s, as they struggled to reconcile the demands of the individual patient with the needs of all patients.

Although NAWCH and the PA took contrasting approaches to lobbying government and health professionals in order to achieve change, underpinning the work of both of these organizations was the notion that the patient, or his or her parent, should have some say in what happened to his or her body. By the beginning of the 1970s the patient had been repositioned as an autonomous actor, and while more emphasis was undoubtedly placed on individual sovereignty, patient groups did

9. For an example of how the orientation of a particular organization changed its focus during this period, see Malcolm Nicolson and G. W. Lowis, "The Early History of the Multiple Sclerosis Society of Great Britain and Northern Ireland: A Socio-Historical Study of Lay/Practitioner Interaction in the Context of a Medical Charity," *Med. Hist.* 46 (2002): 141–74.

not entirely retreat from communal approaches. The patient–consumer conjured into being during the 1960s and 1970s was not a selfish, market-orientated figure: patient groups like NAWCH and the PA were interested in the fate of patients as well as the patient.

Views of the Patient and the Patients' View

This apparently contradictory notion of the patient, as both an individual and part of a group, can be discerned in the new approaches to patienthood being discussed in the 1960s and 1970s. A critical change in the way that patients were viewed, and in the ways in which they came to view themselves, was linked to application of the principles of organized consumerism to health care. Although patients could be said to have operated as "consumers" in the medical marketplace that predated the establishment of the NHS, and patients were afforded some say in the way in which hospital services were managed through mechanisms such as contributory schemes, this kind of patient involvement was not generally referred to in the language of consumption.[10] The introduction of consumerism to health care in the late twentieth century was part of a broader consumer revolution, but as Frank Trentmann points out, this revolution, or series of revolutions, did not automatically turn people into consumers; "political synapses" were necessary bring the consumer into being. New kinds of political traditions and languages came into effect, allowing individuals to connect material experiences with a sense of belonging, interest, and entitlement.[11] More than one type of actor was involved in this process: according to Matthew Hilton and Martin Daunton, the consumer interest was defined by an interplay of political and business interests, varying kinds of expertise, and the activities of consumers themselves.[12] What it meant to be a consumer also changed

10. Mark Jenner and Patrick Wallis, eds., *Medicine and the Market in England and Its Colonies, c.1450–c.1850* (Basingstoke: Palgrave, 2007); Roy Porter, "The Patient's View: Doing Medical History from Below," *Theory Soc.* 14, no. 2 (1985): 175–98; Martin Gorsky, "Community Involvement in Hospital Governance in Britain: Evidence from Before the National Health Service," *Internat. J. Health Serv.* 38, no. 4 (2008): 751–71; Martin Gorsky, John Mohan, and Tim Willis, *Mutualism and Health Care: Hospital Contributory Schemes in Twentieth-Century Britain* (Manchester: Manchester University Press, 2006).

11. Frank Trentmann, "The Modern Genealogy of the Consumer: Meanings, Identities and Political Synapses," in *Consuming Cultures, Global Perspectives: Historical Trajectories, Transnational Exchanges*, ed. Frank Trentmann and John Brewer (Oxford: Berg, 2006), 19–69.

12. Matthew Hilton and Martin Daunton, "Material Politics: An Introduction," in *The Politics of Consumption: Material Culture and Citizenship in Europe and America*, ed. Daunton and Hilton (Oxford: Berg, 2001), 1–32.

over time and place. In the early twentieth century, consumer identity was tied to the development of welfare politics and social citizenship, but by the middle of the century, the "citizen consumer" and the "rational consumer" came into being.[13] During the 1950s, the development of an organized consumer movement concerned with consumers' rights and comparative testing moved consumption "beyond things," to consider public, as well as private, goods and services.[14]

Nancy Tomes has suggested that the term *consumer* was first used in relation to health by American medical economists in the interwar period and taken up again by consumer groups in the United States during the 1960s and 1970s as a way of "liberating" themselves from the paternalism of the doctor–patient relationship.[15] In the United Kingdom, a sustained engagement with the notion of patients as consumers seems to have started in the 1960s, and it came not so much from health economists, but principally from think tanks and consumer groups. One explicitly economic approach can be found in D. S. Lees's *Health through Choice: An Economic Study of the British National Health Service*, produced by the promarket Institute for Economic Affairs (IEA) in 1961. However, such publications were easily outnumbered by those that approached the issue from the consumers' point of view, rather than drawing on economic theory, to make their case. The consumer perspective was paramount in Political and Economic Planning's (PEP) *Family Needs and the Social Services* (1961), the Research Institute for Consumer Affairs' (RICA) *General Practice: A Consumer Commentary* (1963), and Ann Cartwright's *Human Relations and Hospital Care* (1964), which was based on research carried out at the Institute of Community Studies (ICS).[16] All of these groups had connections to the development of organized consumerism in Britain, particularly through the social entrepreneur Michael Young.[17] Moreover, the political affiliation of PEP, RICA, and the ICS was to the left of center, in contrast to the right-of-center, promarket IEA.[18] For organizations like

13. Trentmann, "Modern Genealogy" (n. 11), 43–48.

14. Matthew Hilton, *Consumerism in Twentieth-Century Britain: The Search for a Historical Movement* (Cambridge: Cambridge University Press, 2003).

15. Nancy Tomes, "Patients or Health-Care Consumers? Why the History of Contested Terms Matters," in *History and Health Policy in the United States: Putting the Past Back In*, ed. Rosemary A. Stevens, Charles E. Rosenberg, and Lawton R. Burns (New Brunswick, N.J.: Rutgers University Press, 2006), 83–110.

16. Political and Economic Planning (PEP), *Family Needs and the Social Services* (London: PEP, 1961); Research Institute for Consumer Affairs (RICA), *General Practice: A Consumer Commentary* (London: RICA, 1963); Cartwright, *Human Relations and Hospital Care* (n. 2).

17. On the importance of Michael Young, see Matthew Hilton, "Michael Young and the Consumer Movement," *Contemp. Brit. Hist.* 19, no. 3 (2005): 311–19.

18. For more information on the history of PEP and the IEA, see Andrew Denham and Mark Garnett, *British Think-Tanks and the Climate of Opinion* (London: UCL Press, 1998).

PEP and RICA, consumerism was not about the application of market principles to the NHS; instead, it was a continuation of the ideal of social citizenship upon which the health service had been founded.[19] Such a view emphasized the importance of universal access to care that was free at the point of use as part of the postwar bargain between state and citizen. For RICA, the "adult 'consumers' whom the National Health Service sustains as patients are also those who maintain it as citizens."[20]

Once in use, the language of consumption in health proliferated rapidly: a literature search of British medical and social science journals reveals that one of the earliest references to the consumer appeared in a *Lancet* editorial published in 1961, titled "Patients as Consumers: Wants and Needs." This piece considered the findings of a survey of public services conducted by PEP, a key report that will be discussed in more detail below.[21] A further editorial, published one year later, pointed to the growing activity by consumer groups around health-related topics.[22] The connection of the term *patient–consumer* to the work of consumer groups suggests that these organizations played a key part in introducing the language of consumption, and specifically the notion of the patient as consumer, to the discourse around health. Yet the appearance of the patient–consumer was not merely a semantic shift but was instead representative of wider changes in relationships between doctors and patients, and among patients and health care providers and policy makers. Some evidence that patients themselves were asking for more of a say can be found in the surveys of consumer opinion that were conducted from the early 1960s onward. The very idea that patients' views on public services were worth seeking was a new one in this period. In 1957 PEP conducted one of the first surveys of public opinion about a range of public services including health, welfare, housing, social security, and education. PEP set out to determine the extent to which public services established in the late 1940s "fit present day needs and desires." The survey, PEP contended, was "primarily a study of the consumer point of view."[23]

What PEP found was that satisfaction with public services in general, and the NHS in particular, was high: 86 percent of families reported being satisfied with the attention given to them by their general practitioner, and 95 percent said there was no inconvenient delay in getting into hospital

19. The classic exposition of social citizenship can be found in T. H. Marshall, "Citizenship and Social Class," in *Citizenship and Social Class*, ed. T. H. Marshall and Tom Bottomore (London: Pluto Press, 1992), 3–51.

20. RICA, *General Practice* (n. 16), 4.

21. "Patients as Consumers: Wants and Needs" (n. 6), 927–28.

22. "Patients as Consumers," *Lancet*, May 5, 1962, 957.

23. PEP, *Family Needs* (n. 16), 1–2.

to see a specialist.[24] Complaints were fairly few and far between: some complaint was made about their last visit to the general practitioner by 12 percent of mothers, and 13 percent of individuals questioned had some complaint about their last hospitalization or on some other occasion.[25] PEP concluded that the individuals surveyed thought that "the services are good and [they] are more likely to feel grateful than critical."[26]

Ann Cartwright also found a similar picture of generally high satisfaction in a series of surveys of patients' views on general practice and hospital care conducted on behalf of the ICS during the first half of the 1960s. Cartwright asked respondents if there were any qualities that they felt a general practitioner should have but that theirs lacked: 75 percent could not think of anything. A fifth had some criticism, the remainder did not know.[27] She concluded, "The general picture that emerges from the response to these questions is of satisfied and appreciative patients."[28] But Cartwright also sounded a note of caution: "[B]ehind the satisfaction of most patients there lies an uncritical acceptance and lack of discrimination which is conducive to stagnation and apathy."[29] Indeed, her study of patients in hospitals revealed some potentially troubling issues from the patients' point of view. Although "[t]he majority of patients were satisfied with the medical treatment they received in hospital and had nothing but praise for the nurses and the way they looked after them," a significant proportion identified problems communicating with doctors and other medical staff.[30] Three-fifths of patients reported some difficulty in getting information while they were in hospital, and 23 percent said that they were unable to find out all they wanted to know about their condition.[31] Cartwright contended, "Doctors tend to underestimate both patients' desire for information and their ability to understand explanations. They often seem to discourage patients from asking questions and they sometimes use patients' feelings of respect and deference to evade discussion. . . . If communications are to be improved, some doctors need to be more approachable people, less like inaccessible gods."[32] Bettering communica-

24. Ibid., 100, 114.

25. Ibid., 113, 117.

26. Ibid., 121.

27. Ann Cartwright, *Patients and Their Doctors: A Study of General Practice* (London: Routledge & Kegan Paul, 1967), 7.

28. Ibid., 9.

29. Ibid., 216.

30. Cartwright, *Human Relations and Hospital Care* (n. 2), 10.

31. Ibid., 74.

32. Ibid., 100.

tions was important, Cartwright suggested, not only for increasing patient satisfaction but also for improving the service as a whole. She asserted, "In a National Health Service public opinion could and should be a potent weapon for incentive and improvement. If it is to be effective, it must be based on a knowledge of the facts, and the public needs to recognize that the interests of both patients and staff can be served by informed criticism and demands for improvements."[33]

Indeed, the significance of patient satisfaction surveys like those carried out by Cartwright and PEP was not so much the content of their findings, but that they were conducted at all. As the PEP report remarked, up until that point most other enquires into the NHS had "been concerned with administrative or operational efficiency, and the users of services have mostly been regarded as passive objects. Very little has been heard from those whom the services are designed to serve. In a democratic community this seems a major omission."[34] But the voices of groups and individuals using services were beginning to be heard by the early 1960s. An important mechanism for highlighting such concerns was through the activities of patient organizations. This period witnessed a dramatic upswing in the number of British voluntary organizations in general and around health-related issues in particular. Between 1961 and 1971 approximately 10,500 new organizations became registered charities, and though this rapid growth was partly attributable to a change in charity law, a significant number of important voluntary groups were founded at this time.[35] In the health field, sixty-six new organizations came into being between 1960 and 1979, compared to the fourteen established between 1940 and 1959.[36] The meaning of this development for the position of the patient within British health care is best explored by turning to the first of two case studies: the NAWCH and its campaign around hospital visiting.

33. Ibid., 205.

34. PEP, *Family Needs* (n. 16), 188.

35. Nigel Johnson, "The Changing Role of the Voluntary Sector in Britain from 1945 to the Present Day," in *Government and Voluntary Organisations*, ed. Stein Kunhle and Per Selle (Aldershot: Ashgate, 1992), 87–107, quoted figure on 89. For histories of some of the groups founded in this period, see Helene Curtis and Mimi Sanderson, *The Unsung Sixties: Memoirs of Social Innovation* (London: Whiting and Birch, 2004); and Matthew Hilton, Nick Crowson, and James McKay, eds., *NGOs in Contemporary Britain: Non-state Actors in Society and Politics since 1945* (Basingstoke: Palgrave Macmillan, 2009).

36. Bruce Wood, *Patient Power? The Politics of Patients' Associations in Britain and America* (Buckingham: Open University Press, 2000), quoted figure on 36.

The National Association for the Welfare of Children in Hospital

Up until the late 1940s, it was widely believed that it was undesirable for children in British hospitals to be visited regularly by their parents. Many hospitals permitted parents to visit their children just once a month, or not at all. During the 1950s, however, research carried out at the Tavistock Clinic by the psychologist John Bowlby into "separation anxiety" began to change the opinion of some health professionals and Ministry of Health officials.[37] A film made by Bowlby's assistant, James Robertson, titled *A Two-Year Old Goes to Hospital*, demonstrated graphically the trauma that many children experienced on admission to hospital and spurred the Ministry of Health into action. A committee of the Central Health Services Council was formed under the orthopedic surgeon Sir Harry Platt to investigate the welfare of children in hospital. The Platt Report, published in 1959, recommended that hospitals should allow the unrestricted visiting of children by their parents, and that overnight accommodation should be provided for mothers wishing to stay with their offspring.[38] Initially, the report received little attention, but when the BBC showed excerpts of *A Two-Year Old Goes to Hospital* on television in 1961, and Robertson followed this up with a series of articles in the *Guardian* and the *Observer*, the issue began to gain traction.[39] Jane Thomas, a young mother living in Battersea, south London, got in contact with Robertson and asked what she should do if her own child were hospitalized. Robertson suggested forming an organization, and so Thomas got together with a group of other women and established Mother Care for Children in Hospital.[40] The organization, which became NAWCH in 1965, established branches rapidly across the country. By 1969 NAWCH had fifty branches and three thousand members, and by 1974 the organization had a branch in almost every major city in the country.[41]

37. Harry Hendrik, "Children's Emotional Well-Being and Mental Health in Early Post–Second World War Britain: The Case of Unrestricted Hospital Visiting," in *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century*, ed. Marijke Gijswijt-Hofstra and Hilary Marland (Amsterdam: Rodopi, 2003), 213–42.

38. Central Health Services Council, *The Welfare of Children in Hospital: Report of a Committee of the Central Health Services Council* (London: HMSO, 1959).

39. James Robertson, "The Truth about Settling In," *Guardian*, January 15, 1961, 24; James Robertson, "Maintaining the Bond," *Guardian*, January 22, 1961, 24; James Robertson, "How Parents Can Help Now," *Observer*, January 29, 1961, 33; James Robertson, "Now Over to the Mothers," *Observer*, February 12, 1961, 34.

40. Peg Belson, "To Get Our Agenda onto Other People's Agenda," in Curtis and Sanderson, *Unsung Sixties* (n. 35), 357–70.

41. The National Archives (hereafter TNA), Kew, Ministry of Health Papers (MH) 150/348, National Association for the Welfare of Children in Hospital, note prepared by Ministry of Health attached to memo from Mr. Hewitt to AR Elliott, February 25, 1969.

Initially, NAWCH had one core aim: to get the Platt Report's recommendations around unrestricted hospital visiting and overnight stays implemented.[42] Inspired by the work of Bowlby and Robertson, but also by its own research and experiences, NAWCH developed a series of different techniques for getting hospitals to relax visiting rules. The organization carried out a survey of hospitals asking them about their visiting policies. NAWCH found that although many hospitals said that they allowed unrestricted visiting, the reality could be very different. One hospital stated that "visiting is unrestricted. Although of course we don't allow it in the mornings."[43]Another said, "It is the aim of the Board of Governors to have 'unrestricted visiting' provided that parents understand this does not mean that they can be in the wards all the time."[44] Ear, nose, and throat wards were particularly notorious for their attitude toward the presence of visitors. Some parents were asked to sign a consent form before their child underwent surgery (usually for a tonsillectomy) stating that they agreed not to visit on the day of the operation.[45]

NAWCH drew attention to such practices through press releases summarizing their survey findings. The issue was then taken up by newspapers and raised in a series of questions in Parliament.[46] By 1964, three-quarters of hospitals supposedly allowed unrestricted visiting for parents, but NAWCH sought to ensure that such policies were adhered to by presenting hospitals with leaflets to be given to parents indicating that they could visit whenever they liked.[47] NAWCH also gave hospitals foldaway beds to be used by mothers who wished to stay the night. Such a tactic, described by one early NAWCH member as being "like Greeks bearing gifts," placed pressure on hospitals to liberalize visiting policies in a subtle but persistent way: indeed the organization was always careful to be "nice" to hospitals, refusing to name, for example, hospitals that opposed its efforts for fear of alienating them altogether.[48] Moreover, NAWCH had a powerful ally in the Ministry of Health, and later the Department of Health and

42. Modern Records Centre (hereafter MRC), University of Warwick, MSS.21/1628/1, NAWCH Newsletter, 1970/71.

43. Notes taken by author at NAWCH Roundtable Meeting, Cambridge, June 20, 2009.

44. Quoted in Cohen, *What's Wrong with Hospitals?* (n. 4), 43.

45. NAWCH Roundtable (n. 43).

46. See, for example, "Children (Admission of Mothers)," *House of Commons Debates*, February 24, 1964, vol. 690 cc3–4; "Mothers by the Sickbed," *Guardian*, December 20, 1964, 3; Jacky Gillott, "Welcomed to the Wards?," *Observer*, September 26, 1965, 30.

47. "Mothers and Children in Hospital," *Guardian*, February 25, 1965; Belson, "To Get Our Agenda" (n. 40), 361.

48. NAWCH Roundtable (n. 43).

Social Security (DHSS), who also wanted to ensure that the Platt Report was implemented.[49] The health minister, Kenneth Robinson, spoke at NAWCH's annual conference in 1966, and he met with the organization in 1968 to discuss the problem of children in long-stay hospitals.[50]

Despite opposition from some health professionals and hospital authorities, the discrete pressure exerted by NAWCH, together with ever more insistent memos produced by the Ministry of Health, resulted in the gradual liberalization of visiting policies.[51] By the 1970s, most hospitals allowed unrestricted visiting, and NAWCH began to take on other work, including the provision of low-cost transport for parents of children in hospital and the general welfare of sick children.[52] The organization also became involved in a wider range of health consumer issues, particularly through a deliberate campaign to get its members onto the locally based Community Health Councils (CHCs) from 1973 onward.[53]

On a practical level, NAWCH's work can be rooted in a particular view of the emotional needs of children that was becoming more widely accepted during the 1960s and 1970s. The notion that separating young children from their parents, and particularly their mothers, could cause lasting psychological damage was beginning to find its way into mainstream opinion both inside and outside of the medical profession.[54] Yet, NAWCH's activities and attitudes reflected deeper trends too. Most obviously, NAWCH perpetuated the gendered assumption that it was primarily the mother's responsibility to stay with the sick child. As the organization's initial name, Mother Care for Children in Hospital, made plain, it was women and mothers whom they were appealing to, not men and fathers. This was perhaps unsurprising at a time when women were largely responsible for child rearing, but some NAWCH members held fairly conservative views on bringing up children and the role of women. In 1973, a founder member of NAWCH, Peg Belson, gave a talk titled "Motherhood

49. The Department of Health and Social Security (DHSS) replaced the Ministry of Health in 1968.

50. TNA, MH 150/348, National Association for the Welfare of Children in Hospital, note prepared by MH attached to memo from Mr. Hewitt to AR Elliott, February 25, 1969.

51. MRC MSS.21/1628/5, National Health Service: Visiting Children in Hospital, HM(66) 18, March 10, 1966.

52. MRC, MSS.21/1628/1, NAWCH Newsletter 1970/71; MRC, MSS.21/1628/1/18, NAWCH Annual Report, 1972/3.

53. MRC, MSS.21/1628/1/18, NAWCH Annual Report, 1972/3; MRC, MSS.21/1628/19/1, NAWCH AGM, April 1, 1973; Belson, "To Get Our Agenda" (n. 40), 364.

54. Hendrik, "Children's Emotional Well-Being" (n. 37).

as Career," bemoaning the fact that motherhood "as a full-time occupation, as a career, is more and more being given a secondary role."[55]

NAWCH was clearly not a proto-second-wave feminist group, but that does not mean that its work was insignificant or, in its own quiet way, radical. NAWCH was part of a stream of pre–women's liberation activity in Britain that sought to challenge the consensus on many key topics. As Caitriona Beaumont has shown, even supposedly conservative women's groups, like the Mothers' Union and the Women's Institutes (WI), became involved in important social and political issues during the 1950s and 1960s, such as the campaign for equal pay and the extension of family planning services.[56] Like the WI and the Mother's Union, NAWCH was primarily a middle-class organization, and members did not always appear to understand the difficulties experienced by less affluent mothers with sick children. The group felt that some mothers needed to be persuaded to visit their children in hospital, and did not perhaps appreciate the fact that poorer mothers may have been unable to visit their children regularly because of employment, lack of resources, poor public transport, or other family commitments. Later on NAWCH did begin to address such issues when it launched an enquiry into public transport for parents visiting hospitals, recommending that fares be waived for the parents of sick children as a non-means-tested benefit.[57]

Despite the obvious wider sociopolitical significance of their work, members of NAWCH were uncomfortable with being seen as the political actors that they undoubtedly were. In his address to the fourth NAWCH conference in 1966, the Health Minister Kenneth Robinson made the mistake of referring to NAWCH as a "pressure group," at which, according to a NAWCH member, "[o]ne felt people bristle," but "they relaxed when he charmingly called them a 'most responsible pressure group.'"[58] NAWCH members were careful not to question clinical judgment, "because we weren't in a position to do that," and they worked closely with friendly health professionals whenever possible.[59] Looking back, an

55. MSS.21/1628/29, Margaret Belson, "Motherhood as Career" (paper, National Association for Maternal & Child Welfare Diamond Jubilee Conference, June 27, 1973).

56. Caitriona Beaumont, "Housewives, Workers and Citizens: Voluntary Women's Organizations and the Campaign for Women's Rights in England and Wales during the Post-War Period," in Hilton, Crowson, and McKay, *NGOs in Contemporary Britain* (n. 35), 59–75.

57. MRC, MSS.21/1628/25, Letter from Mrs. Barbara Browse, vice-chairman of NAWCH to the editor of the *Times*, June 7, 1973; MRC, MSS.21/1628/38, Fares Enquiry II: A Position Statement on Fares Assistance, October 1973.

58. MRC, MSS.378/APSW/P/10/27/7a, Fourth Annual Conference of the National Association for the Welfare of Children in Hospital, Report by KS Griffith, n.d. [1966].

59. Belson, "To Get Our Agenda" (n. 40), 361.

NAWCH member was struck by how "polite and feeble" they were, that they took pains not to appear to be aggressive, and that they looked to the more antagonistic PA as an example of what not to do.[60] Other NAWCH members were afraid of being seen as "difficult": partly out of a fear that hospital staff would exact a reprisal on their children, but also because they resented the implication that by asking questions or making certain demands they were moving beyond their expected role. One NAWCH member recalled going to a meeting of the Sheffield Regional Hospital Board and being told, on being introduced to the other members, "'Ah, you're a difficult woman.'" But, she said, she was not being "difficult," she was simply asking questions.[61]

NAWCH's work and attitudes were thus somewhat paradoxical. On the one hand, the organization could appear to be timid and reluctant to challenge professional opinion and power openly. On the other, NAWCH's seemingly passive techniques undoubtedly helped the organization to achieve its aims. Working with, rather than against, hospitals, health professionals, and government officials was probably a wise tactic given the power imbalance between NAWCH and the other actors involved. NAWCH's cautiousness could be seen as being a function of members' age, gender, and social class, but there was also a degree of reluctance on the part of the members to associate themselves too closely with any particular cause beyond their own narrow interests. For example, NAWCH was slow to engage with the nascent consumer movement and its language. Peg Belson, one of NAWCH's founder members, remembered, "We were around at the beginning of the consumer movement if you like, but I don't recall that we were aware of any of that at all. It was a couple of years later that the famous journalist, Mary Stott, wrote about us in the *Guardian* as part of the consumer movement."[62] NAWCH was also careful not to use the discourse of rights to make its case. Belson remarked, "The information about parents' accommodation was never written in terms of rights. There were no patients' rights about it. It was all to do with 'this is the pattern and if you ask. . . .'"[63] It was only later, during the late 1970s, that NAWCH engaged explicitly with the notion of rights, and then the organization was concerned primarily with the rights of the child, not the rights of the parent.[64] Yet, NAWCH did want more say for parents, and in their own quiet way members revolutionized a particular field. They

60. Personal communication with NAWCH member, June 2009.
61. NAWCH Roundtable (n. 43).
62. Belson, "To Get Our Agenda" (n. 40), 360.
63. Ibid., 363.
64. NAWCH Roundtable (n. 43).

may not have framed their protest explicitly in terms of consumerism or patient autonomy, but NAWCH's work did represent a challenge to the conventional methods of hospital care and medical practice. By speaking up for what parents and their children wanted, NAWCH took an important stand not only in the field of pediatric medicine, but also in health care more generally. The presence of groups like NAWCH made it plain that the patients' voice could no longer be ignored completely.

The Patients Association

A somewhat different manifestation of the patients' voice can be found in the work of the PA. Helen Hodgson, a part-time teacher, established the PA in 1963. Hodgson was moved to set up the organization by "reports on thalidomide babies, wrong patient operations and tests on patients."[65] Hodgson and her fellow committee members (who included two lawyers, an engineer, a local government official, and a housewife) were deeply concerned about the issue of patient consent to participate in medical trials or experimental treatment.[66] Hodgson was appalled that "[p]atients are not told if they are receiving new or orthodox treatment. I maintain that they *should* be told."[67] The patient, she asserted, "is entitled to know what treatment, if any, he is receiving."[68] But Hodgson was not just concerned with more information for the individual; she wanted more say for patients collectively. She asserted that the PA aimed "to give a voice to patients, because it believes that any group with a common interest has this right. It does not represent the interests of any one particular group of patients but of all patients."[69]

The wider ethics of human experimentation had, of course, been a matter of interest at the international and national levels for some years. Following the Nuremberg Trials of the Nazi doctors, a series of

65. Contemporary Medical Archives Centre (hereafter CMAC), Wellcome Library, London, SA/PAT/H/1 Press Cuttings Nov 1962–Nov 1963, Letter to the *Sunday Times* from Helen Hodgson, November 25, 1962.

66. Members' occupations listed in "Now a Voice for Patients," *Times*, June 17, 1963, 15. See, for example, the debate sparked by Bradford Hill's article on medical ethics and controlled trials in the *Brit. Med. J.*, which Hodgson took part in, demanding a greater say for patients. Helen Hodgson, "Medical Ethics and Controlled Trials," letter to the *Brit. Med. J.*, May 18, 1963, 1339–40.

67. Hodgson quoted in "Now a Voice for Patients" (n. 66), 15.

68. Helen Hodgson, "Medical Ethics and Controlled Trials," letter to *Brit. Med. J.*, May 18, 1963, 1339–40.

69. CMAC, SA/PAT/H/2, "The Patients Association," Letter from Helen Hodgson in response to Carr's article, in *Hosp. & Health Management*, May 1963.

international regulations governing the use of humans in experiments were established.[70] The Nuremberg Code (1947) stressed the importance of the voluntary participation of the research subject, and the Helsinki Declaration (1964) asserted that researchers should "seek the potential subject's freely-given informed consent, preferably in writing."[71] Domestic codes to regulate human medical experimentation were developed in Britain during the late 1960s, and by the 1970s research ethics committees to govern the use of human subjects had been established.[72] Ethical discussions were also becoming more commonplace in British medical schools and eventually became part of the medical curriculum.[73] Although these measures were symbolically very important, they had less immediate impact on clinical research than might be supposed. Patients were often used in medical trials in both the United Kingdom and the United States during this period without their knowledge or consent.[74] In the early 1960s, an article, and later book, titled "Human Guinea Pigs" by the British physician Maurice Pappworth exposed such practices to public scrutiny. Pappworth detailed a series of experiments conducted on patients in NHS hospitals over the previous twenty years, some of which involved risky procedures such as cardiac catheterization and liver biopsies.[75] Other British

70. Paul Weindling, *Nazi Medicine and the Nuremberg Trials: From Medical War Crimes to Informed Consent* (Basingstoke: Palgrave Macmillan, 2004); Ulf Schmidt, *Justice at Nuremberg: Leo Alexander and the Nazi Doctors' Trial* (Basingstoke: Palgrave Macmillan, 2004); George Annas and Michael Grodin, eds., *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (New York: Oxford University Press, 1995).

71. The Nuremberg Code can be viewed at http://www.hhs.gov/ohrp/archive/nurcode.html, accessed July 11, 2011; World Medical Association Declaration of Helsinki, *Ethical Principles for Research Involving Human Subjects* (Helsinki, 1964), available at http://www.wma.net/en/30publications/10policies/b3/17c.pdf, accessed July 11, 2011.

72. Adam Hedgecoe, "'A Form of Practical Machinery': The Origins of Research Ethics Committees in the UK, 1967–72," *Med. Hist.* 53 (2009): 331–50; Jenny Hazelgrove, "The Old Faith and the New Science: The Nuremberg Code and Human Experimentation Ethics in Britain, 1946–73," *Soc. Hist. Med.* 15, no. 1 (2002): 109–35; Paul Weindling, "The Origins of Informed Consent: The International Scientific Commission on Medical War Crimes, and the Nuremberg Code," *Bull. Hist. Med.* 75 (2001): 37–71; Ulf Schmidt, "Cold War at Porton Down: Informed Consent in Britain's Biological and Chemical Warfare Experiments," *Cambridge Quart. Healthcare Ethics* 15 (2006): 366–80.

73. Michael Whong-Barr, "Clinical Ethics Teaching in Britain: A History of the London Medical Group," *New Rev. Bioeth.* 1, no. 1 (2003): 73–84.

74. For the United States, see David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991). For the United Kingdom, see Hazelgrove, "Old Faith" (n. 72) and Hedgecoe, "'Form of Practical Machinery'" (n. 72).

75. Maurice Pappworth, "Human Guinea Pigs: A Warning," *Twentieth Cent.* 171 (1962): 67–75; Maurice Pappworth, *Human Guinea Pigs: Experimentation on Man* (London: Routledge & Kegan Paul, 1967).

medical scandals during the early 1960s, such as the deformities caused by thalidomide and the treatment of long-stay patients, highlighted the fallibility of modern medicine.[76]

The PA was formed partly in reaction to such "scandals," and the ethical conduct of medical research provided a focus for many of their early activities.[77] Work by Jenny Hazelgrove and Adam Hedgecoe has shown that the association played an important role in getting research ethics committees established in hospitals where clinical research was being conducted.[78] With these committees came wider recognition of the patient's right to informed consent to participate in nontherapeutic research, and to a lesser extent therapeutic research too. But the PA's target was always wider than the narrow application of consent to the experimental setting. Hodgson asserted that "[m]odern medicine creates new issues, moral, economic and practical. The patient should be able to share in both the responsibilities involved and the decisions to be taken. A patient should have no cause to think that he is helpless in the grip of a soulless machine or that he is little more than a clinical specimen or even a sitting duck for students."[79] The PA were established to "represent and further the interests of patients," to improve communication between doctors and patients, to campaign for a greater role for patients in decision making, and to provide a form of consumer protection for patients.[80] Underpinning this work was a belief in patient autonomy: in the patient's right to make decisions about the treatment of his or her body. As a result, PA members began quickly to widen the scenarios where they thought patient consent should be sought.

76. Gordon E. Appelbe, "From Arsenic to Thalidomide: A Brief History of Medicine Safety," in *Making Medicines: A Brief History of Pharmacy and Pharmaceuticals*, ed. Stuart Anderson (London: Pharmaceutical Press, 2005), 243–60; Barbara Robb, *Sans Everything: A Case to Answer* (London: Nelson, 1967); Cmnd. 3687, *Findings and Recommendations Following Enquiries into Allegations Concerning the Care of Elderly Patients in Certain Hospitals* (London: HMSO, 1968); Cmnd. 3975, *Report of the Committee of Inquiry into Allegations of Ill-Treatment of Patients and Other Irregularities at the Ely Hospital Cardiff* (London: HMSO, 1969); Cmnd. 4557, *Report of the Farleigh Hospital Committee of Inquiry* (London: HMSO, 1971); Cmnd. 4681, *Report of the Committee of Inquiry into Whittingham Hospital* (London: HMSO, 1972).

77. For opposing views on the importance of scandal and whistle blowers to the development of bioethics, see Rothman, *Strangers at the Bedside* (n. 74); and Roger Cooter, "The Ethical Body," in *Medicine in the Twentieth Century*, ed. Roger Cooter and John Pickstone (Amsterdam: Harwood, 2000): 451–68; Roger Cooter, "The Resistible Rise of Medical Ethics," *Soc. Hist. Med.* 8, no. 2 (1995): 257–70.

78. Hazelgrove, "Old Faith" (n. 72); Hedgecoe, "'Form of Practical Machinery'" (n. 72).

79. CMAC, SA/PAT/H/1, Letter from Helen Hodgson to *Med. News*, December 23, 1963.

80. CMAC, SA/PAT/H/1, John Gale, "Patients' Association," *Observer*, February 3, 1963; "Now a Voice for Patients" (n. 66) 15; "Patients Association," *Lancet*, January 19, 1963, 151.

A key area of concern for the PA was how patients were used in medical education. Hodgson told the *Guardian* that "the practice of using patients as teaching material without due regard for their dignity as sentient human beings symbolises the kind of contempt or disregard for human feelings which leads to more serious abuses."[81] The association conducted a survey of practices in teaching hospitals in 1963–64, which found that only half of undergraduate teaching hospitals, and a third of postgraduate teaching hospitals, included any reference to their teaching activities in the literature supplied to patients.[82] Moreover, the PA felt that even when the possibility of patients being used in teaching was mentioned, this was often done in an unsatisfactory way. Patients, they argued, should give their explicit consent to the presence of students during clinical examinations or treatment, and, crucially, care should not be conditional on the patient's willingness to participate in teaching.[83] Yet, many hospitals did just this: the PA found that half of London's teaching hospitals refused to treat patients who would not consent to the presence of students.[84] The case of Doris Scott, reported in the *Sunday Express* in July 1965, was far from unusual. Scott refused to remove her clothes in preparation for a gynecological examination in front of a group of male medical students, prompting the consultant and the students to walk out.[85]

The establishment of the Royal Commission on Medical Education in 1965 presented an opportunity for the PA to challenge such practices. The association gave both written and oral evidence on the use of patients in teaching to the commission, chaired by the Nobel Prize–winning biochemist Lord Alexander Todd. The minutes of one of the commission's meetings noted that oral evidence from the PA should be sought not because they believed there was anything much to add to the association's written testimony, but for "quasi-political reasons." This suggested that the PA had become something of an irritant: that its campaign of letter writing to the commission and the Ministry of Health had paid off.[86] The PA told

81. CMAC, SA/PAT/H/1, "The Patient's Voice," Letter from Helen Hodgson to the *Guardian*, February 12, 1963.

82. CMAC, SA/CME/B/156, Written evidence, Patients Association, Addendum, 1967, Press release: "The Patients Association: Survey of Teaching Hospital Leaflets for Patients with Reference to Teaching Activities and Visiting Arrangements."

83. CMAC, SA/CME/B/156, Written evidence, Patients Association, 1965; Letter from Mrs. U Miller, Secretary of the Patients Association to Lord Todd, November 4, 1965.

84. CMAC, SA/CME/B/156, Helen Hodgson, "The Relationship between Patient, Doctor and Student in a Teaching Hospital," n.d. [1965].

85. CMAC, SA/PAT/H/3, "I Won't Strip, Doris Tells a Doctor," *Sunday Express,* July 11, 1965.

86. TNA, ED/129/23, Extract from minutes of the fourth meeting of the Todd Commission, December 22, 1965.

the commission that all patients admitted to teaching hospitals should be warned of the possibility of being used in medical education, that the treatment of patients should not be conditional on their willingness to participate in teaching, and that the consent of the patient should always be obtained.[87] Todd largely agreed with the PA, and the commission recommended in its final report that patients should be "consulted" when being used in teaching and "given a proper understanding of the situation and asked to cooperate." The commission also asserted that "no hospital whatever its status should confine its services to patients who undertake to contribute to medical education," a view shared by the Ministry of Health and the Scottish Home and Health Department.[88]

Although Todd's recommendations were in line broadly with the PA's view, getting hospitals to implement these changes was more problematic. Many of the practices highlighted by the association—such as hospitals' refusal to treat patients unwilling to participate in teaching—continued. The Department of Health did issue guidance to hospitals in 1973 stressing the importance of providing patients in teaching hospitals with an information leaflet and urging hospitals to seek the explicit cooperation of patients in medical education. But Helen Hodgson's own experience at University College Hospital in 1975 suggested that consent was not always sought from patients when students were present, even at the most intimate of examinations.[89] Another Department of Health circular was issued in 1977, reiterating the importance of seeking the patient's consent during teaching, and this gradually became common practice. Indeed, by 1991, patient consent to the presence of students was included in the Conservative government's Patient's Charter as one of the "rights" long held by patients.[90]

The reconstitution of patient consent in teaching as a "right" in 1991 represented a complete turn around by the DHSS. The language of rights was certainly present in earlier discussions about patient consent and the presence of students, but in the 1960s and 1970s it was being used by the PA, not by government officials or medical staff. For the PA, individual patient rights and autonomy were crucial. This can be seen in the way in which the PA viewed the doctor–patient relationship in general and how this should operate in the context of teaching in particular. The PA saw

87. CMAC, SA/CME/B/156, Written evidence, Patients Association, 1965; Letter from Mrs. U Miller, Secretary of the Patients Association to Lord Todd, November 4, 1965.

88. Cmnd. 3569, *Royal Commission on Medical Education 1965–68: Report* (London: HMSO, 1965) 119; TNA, ED/129/23, Letter from Gregson to Hodges, December 161965.

89. For details of Helen Hodgson's complaint against University College Hospital, see CMAC, SA/PAT/E/1/3, Teaching Hospitals.

90. Department of Health, *Patient's Charter* (London: HMSO, 1991).

"the public demonstration and discussion of NHS patients before large classes, frequently without warning or consent" as an "uncivilised relic of the charity days," as the result of "outmoded attitudes to patients dating from a time when hospitals were a charity for the sick poor."[91] The association believed that doctors working in teaching hospitals still treated patients as if they were receiving free or low-cost treatment in exchange for offering their bodies in the service of medical education, a practice that should have been eradicated by the introduction of the NHS in 1948. NHS treatment was, of course, free to all at the point of use, but it also held deeper significance as part of a package of social rights conferred on citizens through the postwar welfare state. Following a brief stay in hospital shortly after the establishment of the NHS, the sociologist Margaret Stacey commented, "I and others like me were fully aware that we had every right to be there, that we paid through our taxes according to our means and that what treatment we had depended on our condition alone: it wasn't charity: it was as of right."[92] Rights to treatment were extended by patient groups like the PA and others to include the right to know what the treatment was and whether or not it was experimental, a right to know what condition the patient was suffering from, a right to some say in the management of the condition, and so on.[93] The PA wanted patients to gain control of their own bodies, and through this they were questioning the notion that doctors alone should decide what was best for patients.

The PA used the language of rights in the context of teaching in two ways. Firstly, the PA believed that not asking patients whether they minded being used in clinical teaching was an invasion of the patient's right to privacy. As Helen Hodgson remarked in the *Daily Express*, patients "are not cranks or prudes. They simply want to be treated as humans—not as specimens. They want the right to preserve their human dignity and modesty."[94] Second, the PA believed that patients should also have a right to refuse to participate in teaching if they so wished.[95] To give these rights legal

91. CMAC, SA/PAT/H/3, Letter from Helen Hodgson to the *Guardian*, "Getting More Doctors More Quickly," February 12, 1965; CMAC, SA/PAT/H/2, "How Am I?," Letter from Helen Hodgson to the *Times*, June 29, 1964.

92. MRC, Private Papers of Margaret Stacey, MSS.184 Box 2: The NHS Complaints Procedure, address by M. Stacey, 1999: The Public Law Project Complaints Forum March 25, 1999. The NHS Complaints Procedure Three Years On: Opening Address by Meg Stacey.

93. For a more detailed discussion of patients' rights within the NHS, see Alex Mold, "'Patients' Rights and the National Health Service in Britain, 1960s–1980s," *Amer. J. Pub. Health* 102 (2012): 2030–38.

94. CMAC SA/PAT/H/2, Colin Riach, "Woman Protests at Being Hospital 'Specimen,'" *Daily Express*, October 10, 1963.

95. CMAC SA/CME/B/156, Written evidence, Patients Association, 1965, Letter from Mrs. U. Miller, Secretary of the Patients Association to Lord Todd, November 4, 1965; CMAC

purchase, the PA began a campaign to create legislation on the issue. In 1969 the PA attempted to get member of Parliament (MP) Brian Walden to introduce a clause in his private members bill (which was concerned with privacy) on patient privacy and teaching.[96] When this proved unsuccessful, the PA worked with Joyce Butler, Labour MP for Wood Green in north London, to craft a patient's bill of rights. After a number of failed attempts to introduce this legislation, the Patients Rights Bill was read in Parliament in April 1974.[97] The bill was intended to "[e]stablish the rights of patients to privacy when receiving hospital treatment under the National Health Service," and it proclaimed that patients had a "right to receive all forms of hospital treatment without any person being present other than those who are necessarily concerned in the provision of that treatment."[98] The bill failed, no doubt in part because health ministers "accepted, as did their predecessors, that this is not a suitable subject for legislation," and officials believed that "[t]he Bill itself is a very slipshod piece of drafting."[99]

Ministry of Health papers suggest, however, that there were more fundamental reasons why the Patients Rights Bill was opposed than due to poor drafting. Officials actively discouraged the use of the language of rights when devising a memorandum on the cooperation of patients in the teaching of medical students. Early drafts of the memo had included reference to the patient's "right to refuse" to being used in teaching, but officials were unsure if any existing legislation actually gave patients a legal right to refuse.[100] Moreover, the Joint Consultants Committee (JCC) of the British Medical Association and the Royal College of Physicians were not keen on developing patients' rights in this area. Commenting on a draft of the memorandum on the use of patients in teaching, the JCC remarked that "it rather under-stressed the importance of clinical teaching while over-stressing patients' rights in this matter."[101] Although the JCC accepted the need for a circular on teaching, it argued that "[m]edical

SA/CME/B/156, Written evidence, Patients Association, Addendum, 1967; Letter from Helen Hodgson to Mr. MW Hodges [secretary of the Todd Commission], March 16, 1967.

96. CMAC SA/PAT/A/1/2, Minutes of the Meeting of the Committee of the PA, December 16, 1969.

97. E.g., "Rights of Patients," *House of Commons Debates*, January 26, 1972 vol. 829 c1404.

98. CMAC SA/PAT/E/1/2, Bill: Rights of Patients, April 10, 1974, presented by Joyce Butler; "Rights of Patients Bill," *House of Commons Debates* April 10, 1974 vol. 872 cc456–7.

99. TNA, MH 160/885, AF Taggart to Dr. Ford re. Rights of Patients Bill, February 29, 1972.

100. TNA, MH 160/1185, FDK Williams to Mr. Chambers, re. clinical teaching, October 16, 1969 and Chambers to Mr. Clark, October 17, 1969, handwritten note on bottom of ibid.

101. TNA, MH 160/1185, Letter from Dr. H Yellowlees [deputy chief medical officer] to Sir John Richardson [JCC chair], March 15, 1972.

science is advancing very rapidly these days and it is in the public interest that our doctors and medical students should be given every opportunity to keep abreast of the latest developments." Teaching, the committee contended, "now takes place in practically every hospital and all patients have an opportunity to make a contribution to this important work."[102]

In contrast to the language of rights and individual autonomy employed by the PA, health officials, senior physicians, and hospitals tended to emphasize the patients' duty to contribute toward clinical teaching and the advance of medicine. An information sheet given to outpatients at University College Hospital in 1972 stated, "This is a Teaching Hospital . . . this may entail the presence of students during the consultation and the consultant may wish to talk to the students about your condition at the same time. Your co-operation is sought in carrying out this important part of the Hospital's duty to the community."[103] Placing emphasis on the collective duty that patients had to society was an example of what Richard Titmuss described as the "Gift Relationship." Although Titmuss used the case of blood donation to illustrate his arguments about the collective nature of medicine and society—that the individual should freely give of himself or herself in order to benefit the community—he stated that he could have used the "giving role of the patient as 'teaching material'" to make the same points. Titmuss noted that patients' "willingness to be 'taught on' and to give of themselves, physically, and psychologically, is presumed. It is taken for granted that in the name of research, the advancement of medical science, society's need for doctors, the better training and more rapid progression of doctors professionally and financially, and ultimately, for the good of all patients irrespective of race, religion, colour or territory."[104] For Titmuss, patients had a duty to take part in the teaching of medical students, not a right to refuse to do so.

Titmuss's work is an example of what David Reubi has called "hemato-social rule," an approach to governing the use of human bodies in medical science that, he suggests, was being replaced by more the more individualistic view inherent within bioethics by end of the 1970s.[105] The PA's campaign to establish a right to consent would seem to run counter to "hemato-social rule," as it emphasized the right of the individual to privacy

102. TNA, MH 160/1185, Extract of aide-memoire from Dr. Grey-Turner to Dr. H Yellowlees regarding meeting with JCC on July 28 [1970].

103. CMAC SA/PAT/E/1/3, University College Hospital: Notes for the Guidance of Out-Patients, April 1972.

104. Richard M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy*, rev. ed. (New York: New Press, 1997), 280–81.

105. Reubi, "Ethics Governance" (n. 5).

over the duty he or she had to participate in medical education in order to benefit the wider community, and thus offers an early preview of the bioethical understanding of the patient.[106] More broadly, the PA's campaign could be seen as one of the first steps away from the kind of social democracy based on social rights and responsibilities envisaged by people like Titmuss, and toward the individualized, consumer-orientated vision of society often associated with neoliberalism. Yet, the PA did not dismiss entirely the collective value of participating in teaching or of the need to think of patients as well as the patient. Hodgson remarked in an article sent to the Todd Commission in 1965 that "[m]ost patients readily accept students as apprentices. . . . They do not object to students learning to be doctors in a practical and natural way. They do object to being used for teaching without warning or consent, to being treated without respect or discretion as a kind of laboratory specimen."[107] What the PA wanted was for patients to have a say in whether or not they were used in teaching, and to participate in decisions about their own medical treatment and the structure of the health service more broadly. Whether the demands of the individual patient were reconcilable with those of all patients was, however, an open question.

Conclusion

Indeed, tensions between the individual and collective view of the patient's role in teaching, and between the patient's rights and the patient's duties, were an ongoing issue for patients' organizations like the PA. These applied not just to the particular problem of consent and the presence of medical students, but also to a range of other considerations. Indeed, it could be suggested that balancing individual wants with collective needs became a key problem for all those involved in health services in the later decades of the twentieth century and into the twenty-first. Patient groups like NAWCH and PA clearly had a part to play in repositioning the patient as an individual. Campaigns around visiting children in hospital

106. On the importance of individual autonomy to bioethics, see Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002). For historical accounts of the development of bioethics in Britain, see Duncan Wilson, "Creating the 'Ethics Industry': Mary Warnock, *In Vitro* Fertilization and the History of Bioethics in Britain," *BioSocieties* 6, no. 2 (2011): 121–41; and Duncan Wilson, "Who Guards the Guardians? Ian Kennedy, Bioethics and the 'Ideology of Accountability' in British Medicine," *Soc. Hist. Med.* 25, no. 1 (2012): 193–211.

107. SA/CME/B/156, Written evidence of the Patients Association to the Todd Commission, 1965.

and the use of patients in teaching drew attention to autonomy, and the extent to which individuals were able to make decisions for themselves, or for their children. Although NAWCH was initially uncomfortable with being labeled as a "consumer group," its particular brand of feminized (although not feminist), seemingly apolitical activism foregrounded a more assertive and questioning patient or parent. The PA was more at home with the consumerist label, but its work was also related to concerns about the ethics of modern medicine.

The repositioning of the patient as an actor in his or her own right within British health care policy and practice can be seen in a number of developments that took place from the mid-1970s onward. The establishment of the CHCs in England and Wales (Local Health Councils in Scotland) was, at least in part, recognition of this shift. Created in 1974 through the reorganization of the NHS, 207 CHCs were established at the local level to be the "voice of the consumer" within the health service.[108] The CHCs also recognized the importance of both individual rights and collective responsibilities, as they took on work that helped individuals, such as assisting patients wishing to make a complaint, but also of wider concern, such as the provision of maternity services and the quality of hospital food.[109] Patients' views, as well as the views of the patient, were being taken increasingly into account. By the end of the 1970s, the patient had been repositioned as a distinct actor within British health politics and policy. Patients, individually and collectively, could no longer be ignored.

The extent to which patient groups like the PA and NAWCH can be credited with such a repositioning of the patient is, of course, hard to quantify. Disentangling the impact of patient–consumer groups from the wider sociopolitical shifts that also helped to drive such changes forward is almost impossible: were patient groups and the issues they fought for the symptom or the cause? Perhaps they were both. The campaigns pursued by patient groups were indicative of broader changes around the place of the individual within society, changes also seen in the rise of bioethics and of consumerism. At the same time, patient organizations had an impact on the development of ethical practices and consumerism, through the issues they drew attention to and through their own refashioning of the patient, not only with the "capacity to reflect and decide," but also to choose and complain.[110] The consequences of the coexistence of the

108. Health Minister Keith Joseph in the House of Commons, *House of Commons Debates,* June 19, 1973 vol. 858, column 380.

109. Jack Hallas, *CHCs in Action: A Review* (London: Nuffield Hospitals Trust, 1976); Ruth Levitt, *The People's Voice in the NHS* (London: King Edward's Hospital Fund for London, 1980).

110. Reubi, "Ethics Governance" (n. 5).

patient as both bioethical subject and autonomous consumer and the ways in which these related, but sometimes conflicting, identities might interact were not yet clear.

Moreover, as even the most casual appraisal of recent changes within the NHS demonstrates, the repositioning of the patient was not a process that concluded in the 1970s. The developments pointed to in this article were the beginning, not the end, of the repositioning of the patient. Further shifts, from the 1980s onward, generated stark conflicts between individual and collective views of the patient. The influence of market models on the provision of health care in Britain resulted in individual patient choice appearing to edge out collective patient voice.[111] Yet the essential dilemma remains: reconciling the demands of a newly assertive patient–consumer with those of the wider population continues to be a key challenge for a taxpayer-funded system like the NHS. How such an impasse may be resolved is a matter for the future, not the past, but recent history suggests that once repositioned as a political actor, the patient is here to stay.

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