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ROLE OF PATIENTS' ORGANIZATIONS IN HEALTH TECHNOLOGY
ASSESSMENT: A HABERMASIAN SYSTEM AND LIFEWORLD PERSPECTIVE

Running title: Role of patients' organizations in HTA

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Abstract

Patient and public involvement in Health Technology Assessment (HTA) is gaining increased interest among research and policy communities. Patients' organizations represent an important link between individual patients and the health system. Social theories are increasingly being used to explain doctor-patient-system interactions, expanding understanding beyond the mere clinical perspective. In this sense, patient involvement in HTA can also be considered through the Habermas' theory of communicative action. From a Habermasian perspective, HTA as part of the instrumental rationality contributes to increased efficiency of resource use within the system; however, such rationalization threatens to colonize the lifeworld by making it *'increasingly state administered with attenuated possibilities for communicative action as a result of the commercialization and rationalization in terms of immediate returns'*. Using Habermasian system/lifeworld framework, this paper explores opportunities and obstacles to patient involvement in HTA, whereby trying to understand current and possible roles of patients' organizations as a mediating force between HTA as a function of the system and the lifeworld, represented by patients.

Keywords

Technology Assessment, biomedical; patient participation; communication; policy; health resources; social theory

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Introduction

Patient and public involvement in Health Technology Assessment (HTA) is gaining increasing interest among research and policy communities (1), and in the same way, as HTA is used to inform health coverage decisions, public and patient interest in HTA has increased (2). However, over the years, to inform the efficient resource use for a growing healthcare demand, a more rapid and less-resource intensive production of HTAs has been imposed (3), resulting in shorter HTA reports (4), limiting patients' and public participation and hampering assessment of the wider implications of using a health technology (5). Countering this, the patient organizations become an important link between individual patients and the health system (6), advocating that patients' perspectives should be fully understood in the deliberative HTA process (2). While patient and public involvement in HTA is usually analyzed under a common framework (7), our analysis is concerned with patient involvement, whereby particular focus is put on the role of their organized form of voicing needs and interests – patients' organizations.

Social theories are increasingly being used to explain doctor-patient-system interactions, expanding understanding beyond the mere clinical perspective (8). Patient involvement in HTA can also be considered through Habermas' theory of communicative action that describes social life through two distinct spheres: the system and the lifeworld, each governed by different rationality; the system being largely a subject of instrumental rationality – orientated towards structure, systematization and successful outputs; whilst the lifeworld is the depiction of the communicative rationality – oriented towards reasoning, interpretation, exchange and achieving mutual understanding (9). Habermas' influential work has been used to contextualize and understand different aspects of health and healthcare, including patient-provider interactions, the role of medicines in society, and patient involvement in research, design and delivery of health services (10-13). Using a Habermasian system/lifeworld framework which helps bridge micro- and macro-social perspectives, this

paper explores the opportunities and challenges to patient involvement in HTA, whereby trying to understand the current and possible role of patients' organizations as a mediating agent between the HTA as a function of the system and the lifeworld, represented by patients.

The system: HTA as a social construct

HTA is a process of critical and systematic assessment that seeks to inform decision-makers about the most efficient use of health technologies, while taking into consideration context-specific social, economic and ethical implications of its use (3). Habermas' system/lifeworld, stemming originally from Marx's interpretations of society and the Parsonian conception of the social system (14), is concerned predominantly with the material exchanges of the society and structuralism, whereby all means, including human beings are utilized for the successful production of actions and outputs (15); and in the context of healthcare - for delivery of health services and production of health gains. Thus, from a Habermasian perspective, HTA as part of the instrumental rationality contributes to increased effectiveness and efficiency of resource use within the system. HTA as a function of health economics attempts to give answers to how scarce health resources can be used to meet patients' needs, while, as argued by Small et al (16), considering that the "predominant production function for health is health care". But, the relevant social consideration of the lifeworld is health, not health care. To the lifeworld, health is not just the product of health care, but of an array of social determinants, and at the same time, access to healthcare is not merely an end-product, but rather a prerequisite for ensuring quality of life and wellbeing (16). Britten (13) categorizes it as a divergence whereby "the lifeworld/system distinction points out the tension between the experiences, needs and concerns of lay people, patients and carers on one hand and, on the other, the need to make profit in a capitalist society (healthcare industry) and the role in enacting government policies [...] Individuals who become ill not only find themselves as members of the familiar lifeworld, but also members of an unfamiliar healthcare system with different rules and modes of behavior" (13) (p.19). In

other words, the rationalization of healthcare through HTA threatens to colonize the lifeworld by making it “increasingly state administered (‘juridified’) with attenuated possibilities for communicative action as a result of the commercialization and rationalization in terms of immediate returns” (12) (p.13). Patient involvement in HTA is one of the possible solutions, that despite **bringing** benefit, also poses challenges, including those of ensuring representativeness and reducing the patient bias that can either stem from their experience with the disease (disease-specific) or be imposed by the industry and technology developers (industry-induced).

The Lifeworld: Patients and HTA

In Habermas’ system/lifeworld dyad, patients and the public represent the lifeworld, where ‘*communicative action*’ plays an essential role that is central to human relationships (14), through which all cultural, experiential and knowledge exchanges occur (9, 13). Within the lifeworld, communication and exchanges have intrinsic value and aim to achieve common understanding without any dominance or power imbalance between individuals (11). In other words, patients’ voice in HTA, brings the lifeworld component of direct participation and experience of those affected by the illness or condition (17). Stewart et al (18) consider that the patient’s contribution to the healing process *includes* “the patient’s personal and subjective experience of sickness; the feelings, thoughts and altered behavior of someone who feels sick” (p.35). Therefore, behavior and thus the influence of patients and their relationship with providers is inevitably bound to the “complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society” (19). **Yet**, patients’ behavior and **personal characteristics such as gender, ethnicity and social class** represent the totality of a person’s learned, accumulated experience, which is socially transmitted through communication, **and inevitably influence the balance of power in achieving the common understanding.**

Patients’ influence on decision-making was explained by Mishler (10) through provider-patient encounters, whereby “the voice of the lifeworld refers to the patient’s contextually-

grounded experiences of events and problems in her life” (p.104). In this sense, the personal identity as conceived by Mead (20) and Durkheim (21) arises as a structure that results from taking over socially generalized expectations, and “an organized set of attitudes that one takes over from one’s reference persons” (22) (p.58). Habermas refers to culture, society and personality as structural components of the lifeworld, where individuality is expressed through the heightened claims to autonomy and self-realization. Thus, beyond the specialized knowledge and system realities, individuality plays a significant role in shaping the communicative action and health outcomes (13), including preferences for decisions made through the HTA process.

Thus, the role of patients in medical decision-making needs to be viewed through its perspective of complex, contextualized and meaningful interaction with the health system, including participation in the HTA process. Increasing access to information, reducing the knowledge gap between providers and patients and deprofessionalization of medicine (12) become enablers for the empowered patient’s negotiation and influence on decision-making, as part of the resistance to the colonization of the lifeworld by either the state or market forces (23).

System-Lifeworld interaction: patient organizations’ role in HTA

A further important aspect of Habermas’ theory is what he termed the colonization of the lifeworld by the system. This is argued to arise in modern societies and it involves increasing systematization of particular areas of the lifeworld, leading to deviation from or stagnation of the original purpose of the lifeworld and its communicative action (11). In terms of patient involvement in HTA, exemplifying the system/lifeworld interaction, such systematization and superimposition could be illustrated through, for example, pressure of the system on the decision-makers to make resource-efficient decisions, shortening the comprehensive HTA analysis and process, manifest as increasingly limited consideration of the wider implications of the use of a health technology. Participants in the HTA process in general are expected to

provide deliberation and guidance for decisions that would ensure efficacy and at the same time fairness in resource allocation. Yet, alongside the intention for ensuring distributive justice, there arises a tension from the systems' rationality to maximize output at an optimal cost, as a prerequisite for them being part of the system and its presupposed efficiency (14). In turn, this leads to limited space for communicative rationality, producing patient dissatisfaction and unmet expectations that represents a failure to reach common understanding (13).

However, patient involvement in HTA, as mentioned earlier, brings challenges and ethical dilemmas into answering the question on how to develop a representative and robust patient-based evidence with minimized disease-specific or industry-influenced patient bias (24). To this end, a strengthened role of patient organizations, emphasizing their mediating power between the bias of the individual experiences and the technocracy of the HTA process, alongside their referential knowledge and expertise gathered from their expert-patient community can respond to some of the challenges and ethical dilemmas, adding quality and objectivity to the patient involvement in HTA process. In a way, patient organizations' mediating power comes from the duality of their role; **on one side**, aligning with the system's rules of efficiency and effectiveness for the purpose of having to sustain their operations and existence, and at the same time being themselves part of the lifeworld, through their constituency – the patients. Thus, it is arguable that their position can be considered more informed than that of the system, in regards to patients' needs and preferences. Patient organizations are accountable before patients as their constituency and *raison d'être*, and are thus expected to be inclined to represent their voice in the HTA process. Yet, often financial support for their work comes from commercial sources with vested interests – namely, the pharmaceutical and technology development industry. As formally registered law-governed entities they are obligated to transparency regarding any contributions that might influence their impartiality in providing inputs in the HTA process (such as in Canada or UK) (25). However, such impartiality has been questioned (26), and

widely debated (27, 28), suggesting that further insights and research is needed on the issue (29). In addition, it is recognized that there is a potential danger in over-representing certain groups, perhaps due to their size, power, influence or even sympathy and that this may not ensure distributive justice is optimized even if they are patient-centered groups and reside more within the lifeworld. However, such concerns are in fact central to Habermas' theories and in particular to the concept of discourse ethics. This involves individuals and groups engaging in communicative acts - what he terms ideal speech situations - to ensure that what is considered appropriate and right is **mutually agreed in** intersubjective terms. The overt influence of certain patient groups in the HTA process is not necessarily a problem if appropriate means of discourse ethics are put in place; this would require all parties in the process to consider both the individual (patient) perspective but also consider rational appeals to universality (in a Kantian sense) and the final decision would be one that recognized and accommodated both these positions for all parties.

Finally, their investment in building independent capacity for patient advocacy and expertise becomes an important currency in maintaining reputation and enjoying recognition by the system as a formal partner in healthcare design and delivery – one that is expected to yield in better quality (and less biased) input to any HTA or policy-making process in a given context (25), and one they are likely motivated to protect at any cost.

Conclusion

However different the system and lifeworld rationalities are, they remain interdependent and in continuous interaction (14, 30). The actual type of interaction between the two spheres – in this case the patient and the HTA process – is what determines the product and the outcome of such interaction. Through the duality of their role, patient organizations can act as mediating agents between the instrumental rationality of the HTA process and the communicative rationality of the lifeworld represented through patients in achieving mutual understanding within the deliberative HTA process. However, there is a fine line between substantial representation of patients' needs and tokenistic approach to their involvement, as

noted by Gibson et al (31), who point out the danger of pathologies that arise with colonization, by lack of attention to service users' own perspectives and treating patients solely as a source of information which *“can be fed into a bureaucratic planning process and a tendency to treat healthcare decision making as a purely technical process, thus privileging the knowledge and expertise of technocrats over that of lay people”*. To this end, it can also be argued that some patient organisations act as instruments to further the colonization of the lifeworld by the system. Thus, enabling articulation of patient voice through strengthened patient organizations participation supports the premise that prioritizing the lifeworld would contribute to better outcomes and more humane treatment of patients as unique human beings, but would also contribute to higher compliance with the recommendations and medical advice provided to them (11).

Conflict of interest

None to declare.

References

1. Gagnon M-P, Desmartis M, Lepage-Savary D, Gagnon J, St-Pierre M, Rhainds M, et al. Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences. *International journal of technology assessment in health care*. 2011;27(1):31-42.
2. Facey KM, Hansen HP, Single AN. *Patient involvement in health technology assessment*: Springer; 2017.
3. Facey KM. *Health Technology Assessment. Patient Involvement in Health Technology Assessment*: Springer; 2017. p. 3-16.
4. Watt A, Cameron A, Sturm L, Lathlean T, Babidge W, Blamey S, et al. Rapid reviews versus full systematic reviews: an inventory of current methods and practice in health technology assessment. *International journal of technology assessment in health care*. 2008;24(2):133-9.
5. Nielsen CP, Funch TM, Kristensen FB. Health technology assessment: research trends and future priorities in Europe. *Journal of health services research & policy*. 2011;16(2_suppl):6-15.
6. Hunter A, Facey K, Thomas V, Haerry D, Warner K, Klingmann I, et al. EUPATI guidance for patient involvement in medicines research and development: health technology assessment. *Frontiers in medicine*. 2018;5.
7. Weeks L, Polisen J, Scott AM, Holtorf A-P, Staniszewska S, Facey K. Evaluation of patient and public involvement initiatives in health technology assessment: a survey of international agencies. *International journal of technology assessment in health care*. 2017;33(6):715-23.
8. Milevska-Kostova N. *Policy Change and Regulation of Primary Care Prescribing and Dispensing in Macedonia—A Qualitative Study*: University of Sheffield; 2017.
9. Habermas J. *The Theory of Communicative Action. Volume 2. Lifeworld and System: A Critique of Functionalist Reason.*: Polity Press, Cambridge; 1987.
10. Mischler E. *The Discourse of Medical Interviews*. Ablex, Norwood, New Jersey; 1984.
11. Barry CA, Stevenson FA, Britten N, Barber N, Bradley CP. Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor–patient communication in general practice. *Social science & medicine*. 2001;53(4):487-505.
12. Scambler G, Britten N. System, lifeworld and doctor–patient interaction: issues of trust in a changing world. In: Scambler G, editor. *Habermas, critical theory and health*: Routledge; 2001. p. 53-75.
13. Britten N. *Medicines and society: patients, professionals and the dominance of pharmaceuticals*: Palgrave Macmillan; 2008.
14. Cuff EC, Dennis A, Francis DW, Sharrock WW. *Perspectives in sociology*: Routledge; 2006.
15. Finlayson JG. *Habermas: A very short introduction*: OUP Oxford; 2005.
16. Small N, Mannion R. A hermeneutic science: health economics and Habermas. *Journal of Health, Organisation and Management*. 2005;19(3):219-35.
17. Wong-Rieger D. Moving from patient advocacy to partnership: a long and bumpy road. *The Patient-Patient-Centered Outcomes Research*. 2017;10(3):271-6.

18. Stewart M, Brown JB, Weston W, McWhinney IR, McWilliam CL, Freeman T. Patient-centered medicine: transforming the clinical method: CRC press; 2013.
19. Tylor EB. Primitive culture: researches into the development of mythology, philosophy, religion, art, and custom: J. Murray; 1871.
20. Mead GH. Mind, Self, And Society, From The Standpoint of a Social Behaviorist. C.. Morris), Chicago: The University of Chicago Press; 1972.
21. Durkheim E, Halls W. The Division of Labour in Society [De la division du travail social]. Basingstoke: Macmillan; 1984.
22. Habermas J, Press P. The Public Sphere: An Inquiry into a Category of Bourgeois Society. Cambridge: Polity Press; 1989.
23. Williams G, Popay J. Lay health knowledge and the concept of the lifeworld. In: Scambler G, editor. Habermas, critical theory and health: Routledge; 2001. p. 33-52.
24. Staniszewska S, Werkö S. Patient-based evidence in HTA. Patient involvement in health technology assessment: Springer; 2017. p. 43-50.
25. Wong-Rieger D. Discussion: Patient Participation in HTA—Evidence of Real Change? Patient Involvement in Health Technology Assessment: Springer; 2017. p. 373-80.
26. Herxheimer A. Relationships between the pharmaceutical industry and patients' organisations. *BmJ*. 2003;326(7400):1208-10.
27. Kent A. Should patient groups accept money from drug companies? Yes. *Bmj*. 2007;334(7600):934-.
28. Mintzes B. Should patient groups accept money from drug companies? No. *BMJ*. 2007;334(7600):935-.
29. Rose SL, Highland J, Karafa MT, Joffe S. Patient advocacy organizations, industry funding, and conflicts of interest. *JAMA Internal Medicine*. 2017;177(3):344-50.
30. Baxter H. System and Life-World in Habermas's " Theory of Communicative Action". *Theory and Society*. 1987:39-86.
31. Gibson A, Britten N, Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health*:. 2012;16(5):531-47.