



Researching involvement in health care practices: interrupting or reproducing medicalization?

Sara Donetto PhD¹ and Alan Cribb PhD²

¹Post-doctoral Fellow, ²Professor of Bioethics and Education, Centre for Public Policy Research, Department of Education and Professional Studies, King's College London, London, UK

Keywords

epistemic involvement, medicalization, patient involvement, research paradigms, shared decision making

Correspondence

Dr Sara Donetto
Centre for Public Policy Research
Department of Education and Professional Studies
King's College London
Franklin Wilkins Building
Waterloo Road
London SE1 9NH
UK
E-mail: sara.donetto@kcl.ac.uk

Accepted for publication: 14 June 2011

doi:10.1111/j.1365-2753.2011.01725.x

Abstract

In this paper we reflect upon and problematize the ways in which 'patient involvement' is interpreted in a substantial proportion of the research literature on involvement and shared decision making. Drawing upon an analysis of this literature we raise concerns about the 'medicalization of involvement' embedded in, and reproduced by, some dominant research lenses, suggesting that this medicalization has powerful discursive and material effects. For example, we suggest that it tends to normalize and arguably trivialize intrinsically problematic and contentious concepts such as 'patient preferences' and, at the same time, to obscure the full range of possibilities for reciprocity in the exchanges between the medical world of the professional and the experiential and narrative world of the patient. We argue that richer conceptualizations of collaboration in clinical work are both possible and very much needed, and we indicate some examples of scholarly resources and perspectives that point towards richer and more defensible accounts of involvement. Overall we call for more attention to the idea of 'epistemic involvement' and much greater cross-fertilization between different epistemological paradigms in this area of research.

Introduction

In this paper we reflect upon and problematize the ways in which 'patient involvement' is interpreted in a substantial proportion of the research literature on involvement and shared decision making. Existing work on involvement in clinical encounters is dominated by research studies that aim to define, measure and standardize the main features, rationales and health outcomes of collaborative forms of practitioner–patient interaction. The conceptualizations of involvement in this dominant body of work are, we are suggesting here, largely framed by biomedical perspectives. The 'medicalization of involvement' embedded in, and reproduced by, these research lenses has powerful discursive and material effects. For example, it tends to normalize and thereby trivialize intrinsically problematic and contentious concepts such as 'patient preferences' and, at the same time, to obscure the full range of possibilities for reciprocity in the exchanges between the medical world of the professional and the experiential and narrative world that the patient brings to the consultation. In this paper we argue that richer conceptualizations of collaboration in clinical work are both possible and very much needed, and more specifically we propose that

much greater dialogue and cross-fertilization between different research paradigms and traditions would be an important step in this direction. In the final section we indicate some examples of scholarly resources and perspectives that point towards richer and more defensible interpretations and possibilities of involvement.

Dominant discourses of involvement and shared decision making

For at least two decades, UK and US health policy and professional guidance have promoted a progressive transformation of health care towards more inclusive and participative philosophies and practices. In both countries scepticism towards the idea that physicians 'know best' and necessarily act in the 'best interest' of patients, and concerns about the ethical issues around patient consent and about the escalation of health care costs can be dated back to the 1980s [1,2]. In the UK, the new centrality of patient choice to service delivery was officially signalled by the 1989 Department of Health White Paper 'Working for Patients' [2,3]. Numerous subsequent policy documents have drawn attention to the increasingly prominent role of discourses of participation in

UK health care, especially in the last decade [4–6], while recent official guidelines have enshrined the centrality of involvement and shared decision making to all prescribing processes [7,8].

These broad trends in the direction of health policy suggest a relatively uniform process of ‘transformation’, that is, a process of wholesale and orchestrated change in health care relationships. Of course things are less simple, and very much less coherent, in practice. The diversity of approaches to and understandings of new modes of communication/interaction in health care is apparent in the foci and emphases of the accompanying research literature. In the remainder of the paper we reflect on the dominant discourses of involvement as we identified them in the literature on shared decision making (often referred to as SDM). Although shared decision making is, of course, only one possible construction of, and facet of, patient involvement, we would argue that this body of work merits prominent treatment because it is the focus of a considerable proportion of research within the field,¹ and we would suggest is usefully illustrative of the influence of ‘medical model’ work in the area of patient involvement.

Although we did not undertake a full systematic review of the literature, we examined, in addition to policy literature, 106 peer reviewed articles on involvement in decision making identified through keyword searches of medical, social science and general databases (e.g. PubMed, Web of Knowledge, Google Scholar). Our analysis showed a wide variety of research trajectories, theoretical underpinnings and outcome indicators indicative of a high level of theoretical fragmentation and of a ‘weakly organized’ body of work, that is, work that runs on parallel lines without cross-referral. Some degree of very general consensus exists: first, around the importance of the principles established by the seminal work by Charles, Gafni and Whelan, specifying that in shared decision making: (1) at least two participants – usually physician and patient – are involved; (2) both parties share information; (3) both parties take steps to build a consensus about the preferred treatment; and (4) an agreement is reached on the treatment to implement [1,9]. And second, around the notion that SDM is a model of interaction that is situated somewhere between, or beyond, the paternalistic (the physician decides) and the informed (the patient decides) models and their variants [1,9–13].

Although efforts towards identifying a sharper ‘formula for’, and definition of, SDM – such as the interesting ‘integrative model’ proposed by Makoul and Clayman in their review of the most influential work on shared decision making – exist, recent reviews lament a persisting lack of clear definitions for shared decision making in the existing literature [14,15]. Research into patient involvement and shared decision making has, over the years, proliferated along several different axes, including: the description of competences and stages required by shared decision making [16]; the exploration of patients’ views [17–22]; the identification of factors that facilitate and/or hinder partnership frameworks of clinical practice [23,24]; the review and production of instruments for the measurement of patients’ active involvement in

clinical consultations and decision making [25–27]; the impact of decision support tools on illness management, interaction dynamics and health outcomes [11,28–30]; and the analysis of practices across different geographical areas [31].

Tracing clear boundaries around the various areas of research in this field is practically impossible. In addition, some clinical areas have spawned significantly more work on patient involvement and shared decision making than others. This is the case for medical fields in which the nature of the clinical condition requires the patient to take an active role in their own care either to self-administer medication, to monitor clinical or biochemical indicators, or to make complex treatment decisions. In the area of diabetes management, for example, where the role of patient self-management is prominent, research has been carried out on disparate aspects of patient involvement: from its effects on metabolic control [32], to the relationships between involvement in decisions and self-management [33–35], to the scope for the use of decision aids [36]. The complexity of treatment choices and of the trade-offs between probability of survival and quality of life these choices entail have made patient involvement an important area of investigation in the context of the clinical management of cancer (e.g. in the area of breast cancer) [37–42]. Also, research on the importance of patient involvement in decision making is notable in fields in which the evidence for the most appropriate treatment is weak or not incontrovertible or the research on issues of medicalization of physiological conditions is well established (e.g. studies looking at the management of menopause-related symptoms [43–46]; and at relevant decision aids [28,29,47]).

On the other hand, despite the existence of extremely promising work on the involvement of patients suffering from psychotic illnesses in the decisions regarding their crisis care [48,49], relatively little information is available, for example, on the involvement of patients in the routine management of depression in primary care [50,51]. Research is also relatively sparse in the case of common clinical scenarios such as asthma management [52,53], or cardiovascular risk prevention through statins [54], and in the case of complex and traditionally more participative settings such as HIV care [55].

The medicalization of involvement

The literature examined – as we have tried to indicate – shows a high degree of fragmentation of focus and approach combined with an intense striving towards a systematization of practices of involvement. We would suggest that these efforts towards systematization continue to fail partly because they are underpinned by a partial (and unnecessarily polarized) construction of what involvement is, what it looks like and what it is for. In particular we would argue that in much of the work discussed above analytical frameworks are constructed in ways that broadly correspond with biomedical interests and perspectives and associated scientific epistemologies. These biomedical understandings of patient involvement, we would suggest, tend not to make enough room for or meaningfully take into account multiple perspectives on what clinical encounters, communication and decisions can and should be about and also, for the same reason, provide a partial – that is, limited and ‘one-sided’ – account of what takes place in everyday clinical exchanges. We should stress that here we are not referring to the interests and perspectives of individual clinical practitioners

¹ It is worth briefly noting another limitation of this account – a limitation that reflects much of the existing published work in the field – namely the habitual treatment of clinician–patient interactions as dyadic. Of course all clinical interactions are embedded in complex networks of relations (with different health professionals, administrative staff, relatives, friends, online communities, etc.), but we do not address this simplification here as it is not central to our theme.

– because, of course, these can be very diverse – but rather to background ‘logics’ and tendencies that shape analytical frameworks in this domain.

The discursive and material effects of these polarized constructions of involvement are directly observable. These effects highlight the concrete implications of currently dominant discourses, circulating in and through research, and illuminate the ways in which these discourses can constrain thinking by reproducing only partial understandings of involvement. The examples we offer here are merely indicative – they are a very brief illustration of, and summary of, what we mean by the partiality of dominant accounts and why we believe it is a significant problem.

The literature on shared decision making makes frequent reference to the importance of eliciting and taking into account ‘patient preferences’, but it rarely examines what exactly count as ‘patient preferences’, and exactly why they matter. This is so despite the very fundamental, far-reaching and well-recognized complications these issues throw up in philosophy, sociology and psychology discussed, for example, in relation to: the complex relationship between preference satisfaction and well-being, or the hazy but important boundaries between wants and needs [56,57]; the shifting, hybrid and layered nature of identity, and the multiple other unstable factors that ‘structure’ or construct agency and its expressions [58,59]; the difference between ‘classic rational’ and ‘heuristic’ models of preference formation and elicitation and, more generally, the mediating effects of all ‘choice architectures’ [60,61].

The emphasis of the dominant research paradigm, as revealed in the literature we examined, is on ‘clinical operationalization’, that is, it is not just that ‘involvement’ and related concepts including ‘patient preferences’ are translated into concepts that are sharply defined, standardized and measured but that this is typically done in a way that fits into existing systems, models and practices of clinical decision making. It is as if – to exaggerate to make the point – ‘patient preferences’ exist essentially as an extra piece of hard data that needs to be added to the technical algorithms of clinical reasoning. (Of course we are not suggesting that any individual actually thinks in these terms, we are merely reflecting on the background drivers and framing of certain currents of work.) In practice, we are suggesting that this emphasis, for example, can encourage the notion that a patient’s ‘preferences’ are pre-existing, stable and/or easily elicited – a notion that does not stand up to critical examination in practice in many cases. The complexity of clinical encounters (e.g. acquiring and making sense of medical information, coming to terms with changing possibilities, managing emotions, evaluating options and envisaging possible futures) is reduced to the formation and elicitation of simple and ‘mere’ preferences.

To complicate things even further, a significant amount of research aims at exploring and identifying ‘patient preferences’ with regards to their degree of involvement in clinical decisions. If these research exercises take place within frameworks in which involvement is understood largely from biomedical perspectives, however, their scope remains very limited. While they can provide information on patients’ views and inclinations in relation to preformed notions and practices of involvement, they may fail to interrogate different meaning-making systems in order to come to a genuinely shared notion of what involvement might be or should be.

Another closely related simplification is that current mainstream understandings of clinician–patient ‘collaboration’ lack a signifi-

cant dimension of reciprocity. Involvement is most commonly framed as ‘patient involvement’. While a lot is said about the ways in which patients should be involved in clinical care, the nature of ‘collaboration’ for the professional and in particular the idea of, and scope for, the health professional’s ‘involvement’ is much less clear. We are told in detail about the ways in which patients can share, and benefit from, an understanding of illness and illness management that is grounded in biomedical rationales. Much less attention is paid to the scope for the practitioner entering the patient’s world of knowledge and experience and trying to ‘make sense’ of what reality looks like, and feels like, for the patient.

We do not want to suggest that the importance of mutual engagement in the clinical relationship has not been widely recognized in the traditions we have considered. Its importance was clearly stated by Charles, Gafni and Whelan [9], and more than 10 years earlier, Tuckett and colleagues had endorsed the idea that a consultation ‘can be considered as a meeting between systems of beliefs and ideas’ and ‘that a priority activity for consultations is the task of allowing an exchange or sharing these systems of belief’ [62]. Rather we are noting the markedly uneven way in which these broader discursive acknowledgements have been taken up and developed within most related research programmes. Some recent studies have highlighted the importance of this imbalance in involvement, but even these have failed to seriously interrogate it [2,15,63].

We are arguing for richer analyses of the layers and dynamics of clinical encounters, and in particular for serious consideration to be given to the patient’s point of view not only in terms of preferences but also in terms of constructing and understanding *the problem* from the patient’s perspective [64]. We certainly do not intend to overlook the crucial importance of professional expertise and judgement for the accurate weighing of complex clinical, practical and ethical factors. But we want to emphasize that the forms of understanding we are referring to here entail engagement with the patient’s systems of meaning and ways of making sense of health and illness, and thus a critical challenging of narrow conceptualizations of the clinician’s involvement. It entails, in other words, genuinely open approaches to epistemological difference as a component of professional competence, and certainly not any abdication of professional competence or judgement. We stress that if involvement remains – as it predominantly is now – crafted by professionals and policy makers, if the input of public/patients is cast in the currency of biomedical values, if the worlds that come into contact are not properly permeable to each other at a deep level (of spheres of meaning) but only at a superficial level (of options setting and preference elicitation), then we will remain trapped within self-limiting conceptions of involvement.

Interrupting medicalization in involvement scholarship

The partiality of dominant constructions of involvement becomes apparent when alternative traditions are explored with a view to framing the notion of involvement in a way that does justice to its inherent complexity and contestability. Here we provide just a few examples of research approaches that should, we argue, be given greater voice and weight in this area of practice analysis. An authentically inclusive analysis of what involvement means for different groups of people – patients, health professionals, carers,

policy makers, academics – would involve allowing for the interplay of different logics. We are not suggesting that existing understandings should be written off, but that it is important to invite and explore conceptualizations of involvement that are rich enough to incorporate, combine or somehow bring into conversation several competing discourses.

We have already cited Entwistle and Watt's call for more careful consideration of the multidimensional nature of 'involvement' [64]. In the field of clinical communication, Salmon and Young invite researchers to constantly re-examine dominant metaphors for clinical relationships, seeking to unpick their imperfections, challenge their assumptions and, where necessary, replace them with more adequate metaphors [65]. We suggest that an analogous broadening of conceptualization processes should increasingly frame and underpin scholarship on the practices of patient involvement and shared decision making. Our starting assumption is summarized in Cook and McCarthy's argument that the 'multiple and complex nature of self and identity' makes it imperative for health professionals as much as social scientists to engage and deal with this complexity; that 'we need both a sociological and medical framework in which both the biological and social bodies are considered' [66].

Work on the experience and significance of 'involvement' from the perspective of the 'lifeworlds' of patients tends to be scattered here and there in the existing literature on involvement. It can usually be more easily found in work that is methodologically closer to non-medical research traditions; for example, work on identity, illness narratives and conversation features in the clinical setting.

In the field of psychology and psychotherapy, for example, Tilden and colleagues examine the symbolic meaning of non-adherence to insulin treatment for a young woman suffering from Type-1 diabetes, showing the importance of thinking about participation and adherence in terms of identity work [67]. Using a wide-ranging approach to understanding the formation of health identities and their relational and individualized character, Fox and Ward illustrate the potential of 'maps of identities for understanding much more about "health" behaviour, "health" beliefs and patterns of morbidity and health care provision and consumption' [68]. Similarly Mathieson and Stam explore the processes of identity renegotiation in the lives of people suffering from cancer and the effects of encounters with medical institutions on the unfolding of patients' illness narratives [69]. Also emphasizing the value of attending to patients' accounts of their illness experiences, the study by Haidet, Kroll and Sharf shows that it is possible to develop a conceptual model of 'patient participation in communication and illness care' from the analysis of narratives rather than from surveys on involvement preferences [70].

We would suggest that these perspectives should not be neglected in any serious examination of involvement. We also want to stress the central importance of paying more attention to the social contexts in which narratives unfold and health behaviours are negotiated [71]. The extensive work on the narratives of menopause and hormone replacement therapy (HRT) treatment in New Zealander women's accounts carried out by Stephens and her colleagues reminds us of the value of analysing discursive practices in order to better understand how people – women in this case – position themselves and make or defend choices in relation to the management of their symptoms [71–73].

Finally, very useful insights can also be found in the literature on health activism and patient organizations, and in particular on the involvement of patient organizations in research. Scholarly work in this area examines the nature of patient organizations' relations with the medical and other professions and the relationships between lay (i.e. experiential) and expert knowledge(s). Useful suggestions can be found, to mention only one example, in Rabeharisoa's analysis of the 'partnership model' of interaction between lay and expert organizations in the case of neuromuscular disease organizations in France [74]. More precisely, in the author's exploration of how, in the case of spinal muscular atrophy, as a consequence of this sort of interaction '“experiential” knowledge and scientific knowledge on the disease ended up forming an indivisible whole, jointly influencing clinical profiles and trajectories of life with the disease' (p. 2133). The possibilities for interactions in which 'patients are neither laypersons who have simply acquired academic knowledge to dialogue better with specialists, nor patients who reject scientific expertise in the name of the irreducible nature of their experience with disease' (p. 2134) described by Rabeharisoa in the arena of clinical research can translate to the context of the clinical encounter. Scholarly analyses of the frameworks for interaction developed between professionals and patients/carers in clinical research contexts could provide useful insights for attaining more genuinely participative practices in health care more broadly.

All the currents of work reflected in the few examples we have drawn upon show the potential for involvement scholarship to challenge, and hopefully transcend, medical models. Their importance in this context derives from varying degrees of commitment to what might be called 'epistemic involvement', that is, taking patients' perspectives seriously not as an extra source of data to feed into clinical epistemologies but as a source of epistemically alternative framings and insights. Neither the practices of, nor the study of, patient involvement seem to us to be ultimately viable – methodologically or ethically – unless underpinned by some meaningful engagement with 'epistemic involvement'. In advocating methodological pluralism and the crossing of epistemic and paradigmatic boundaries we are not naively imagining some giant universal synthesis of knowledge. We are very conscious that there will inevitably be tensions and conflicts, as well as complementarities, generated by the process. In particular, as we have indicated, the research conversations we are advocating suggest real limits to projects of clinical or research standardization (although they do not mean there is no role for standardization providing these limits are understood and acknowledged). However, it seems to us that here, as elsewhere, tidiness can only really be accomplished within the context of untidiness, and that the gains to be garnered from embracing complexity far outweigh any losses.

Conclusion

Although relatively limited in number, the studies mentioned above are very significant examples of work that can further illuminate and deepen our thinking around, and approaches to, patient involvement and challenge the limited models that are often used to construct this dimension of clinical care. We would suggest that if scholarship on involvement is to contribute to a real interruption of, rather than an ever more circuitous reproduction of, medicalization then thought needs to be given to ways of promoting – in

theory and in practice – more porous disciplinary boundaries in involvement-related research. Our conclusion is that more cross-fertilization between different epistemological paradigms is vital to more representative, more realistic – and therefore more useful – conceptualizations of involvement.

Funding acknowledgements

This work was made possible because of the award of an Arts and Humanities Research Council (AHRC) Fellowship (Grant No. AH/F008678/1) to Alan Cribb; we are very grateful to AHRC for this support.

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