



UNIVERSITY
OF WOLLONGONG
AUSTRALIA

University of Wollongong
Research Online

Faculty of Social Sciences - Papers

Faculty of Social Sciences

2015

Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies

Mette Kjer Kaltoft

University of Southern Denmark, mettekjerkaltoft@rsyd.dk

Jesper Bo Nielsen

University of Southern Denmark

Glenn P. Salkeld

University of Wollongong, gsalkeld@uow.edu.au

Jack Dowie

University of London

Publication Details

Kaltoft, M., Nielsen, J., Salkeld, G., & Dowie, J. (2015). Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies. *Studies in Health Technology and Informatics*, 218 172-177.

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library:
research-pubs@uow.edu.au

Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies

Abstract

'Symbolic violence' is committed, however well-intentionally, by the imposition of particular conceptualizations of what information, in what form and quality, is needed in order to make an 'informed choice' and hence – by questionable segue - a high quality decision. The social and cultural forms of relevant cognitive capital possessed by those who fail, because of their low general literacy, professionally-set knowledge tests of functional health literacy, are being ignored. Failing to recognise and exploit a particular form of functional decision literacy, in fact leads to symbolic violence being experienced by individuals at any and all levels of general literacy. It leads many to adopt the same range of avoidant and other undesirable strategies within healthcare situations observed in those of low basic literacy. The alternative response we propose exploits the alternative generic decision literacy which comes in the form of the ability to access and use the decision-relevant resources provided for many consumer services and products on comparison websites and magazines. The methodology is the simple form of multi-criteria analysis in which the products' ratings on multiple criteria are combined with criterion weights (supplied by the site) to produce scores and 'best buys' and 'good value for money' verdicts. Our alternative approach extends this approach to healthcare options and permits the incorporation of personal criterion weights in furtherance of person-centred care. Health informaticians, especially those in the decision support field, should build on this widespread generic competence. The fact that it is generic, far from implying context insensitivity, can be seen as a necessary basis for achieving context-sensitivity and sensitivisation at the level of the individual person as they experience a lifelong sequence of healthcare decisions.

Disciplines

Education | Social and Behavioral Sciences

Publication Details

Kaltoft, M., Nielsen, J., Salkeld, G., & Dowie, J. (2015). Health informatics can avoid committing symbolic violence by recognizing and supporting generic decision-making competencies. *Studies in Health Technology and Informatics*, 218 172-177.

Health Informatics Can Avoid Committing Symbolic Violence by Recognizing and Supporting Generic Decision-making Competencies

Mette Kjer KALTOFT^a, Jesper Bo NIELSEN^a, Glenn SALKELD^b, Jack DOWIE^c

^a*Department of Public Health, University of Southern Denmark*

^b*School of Public Health, University of Sydney*

^c*London School of Hygiene and Tropical Medicine*

Abstract. ‘Symbolic violence’ is committed, however well-intentionally, by the imposition of particular conceptualizations of what information, in what form and quality, is needed in order to make an ‘informed choice’ and hence – by questionable segue - a high quality decision. The social and cultural forms of relevant cognitive capital possessed by those who fail, because of their low general literacy, professionally-set knowledge tests of functional health literacy, are being ignored. Failing to recognise and exploit a particular form of *functional* decision literacy, in fact leads to symbolic violence being experienced by individuals at *any and all* levels of general literacy. It leads many to adopt the same range of avoidant and other undesirable strategies within healthcare situations observed in those of low basic literacy. The alternative response we propose exploits the alternative generic decision literacy which comes in the form of the ability to access and use the decision-relevant resources provided for many consumer services and products on comparison websites and magazines. The methodology is the simple form of multi-criteria analysis in which the products’ ratings on multiple criteria are combined with criterion weights (supplied by the site) to produce scores and ‘best buys’ and ‘good value for money’ verdicts. Our alternative approach extends this approach to healthcare options and permits the incorporation of personal criterion weights in furtherance of person-centred care. Health informaticians, especially those in the decision support field, should build on this widespread generic competence. The fact that it is generic, far from implying context insensitivity, can be seen as a necessary basis for achieving context-sensitivity and sensitivisation at the level of the individual person as they experience a lifelong sequence of healthcare decisions.

Keywords. Informed choice; health literacy; person-centred care; empowerment

Introduction

A recent paper questions the focus on *functional* literacy in attempts to encourage and support the making of ‘informed’ healthcare choices [1]. Drawing on the work of Bourdieu, Adkins and Corus see ‘symbolic violence’ being committed, however well-intentionally, by the imposition of particular conceptualizations of what information, in what form and quality, is needed in order to make an ‘informed choice’ and hence – by questionable segue - a high quality decision. These conceptions are built into the definitions of health literacy by WHO and the EU and have major policy and resourcing

implications[2]. The social and cultural forms of capital possessed by those who fail, because of their low general literacy, to pass professionally-set knowledge tests of functional health literacy, are being ignored, say Adkins and Corus. These individuals are being characterised, however implicitly and politely, as having deficiencies that need eliminating or at least reducing. 'A substantial amount of research concludes low literate individuals are incapable of taking on the tasks associated with healthcare and such disempowering depictions of low literates propagate stereotypes and biases toward the undereducated and perpetuate disparities and gross inequities in healthcare services...Those who fall short of standard expectations experience denigration, leaving them with no command for social respect.' The experiences of symbolic violence create concerns of being ridiculed and these manifest themselves in avoidance and other strategies inimical to optimal healthcare decision making, producing consequences such as non-adherence.

In this paper we accept the validity of this argument, but move away from its concern with low general literacy to argue that failing to recognise and exploit a particular form of functional *decision* literacy, in fact leads to symbolic violence being experienced by individuals at *any and all* levels of general literacy. It leads many to adopt the same range of avoidant and other undesirable strategies within healthcare situations observed in those of low basic literacy. Our alternative response exploits that form of generic decision literacy. It offers support that does not imply that only an 'informed choice' can be a good decision, with 'being informed' defined professionally. It focuses on the vacuum left at the Point of Decision in the formal definitions.

The argument is most effectively made with reference to what we see as the current orthodoxy within the decision-aiding branch of health informatics. This orthodoxy is grounded in the IPDASi guidelines [3], but encompasses the specific interpretations in publications that proclaim their adherence to them. We can also endorse the conclusion of Joseph-Williams, Elwyn and Edwards, reviewing research into the patient experience, that knowledge is not power, and that information is not in itself empowering unless deployed (deployable) within a more equal clinical power relationship [4]. But we disagree with their assumption that knowledge in the conventional form is to be regarded as a necessary condition, albeit now one of two. We argue that supplying the information in a particular 'unconventional' form and integrating it with the best available estimates, will enable the patient to arrive at an informed decision, even if they know nothing about its content in the sense the orthodoxy seeks. Some patients will wish to engage in the orthodox way. We are concerned with those who will experience this requirement as symbolic violence, as a result of which they will adopt attitudes and behaviours not conducive to optimal health, self-defined. The relative numbers are not known, but may be large.

Our case for a generic approach may appear to endorse or encourage context-insensitivity. Almost the opposite. The argument is that a generic and widely available 'decision language' is essential if context-sensitivity is to be successfully achieved by the individual patient/person in their lifelong sequence of healthcare decisions. To seek to achieve context-sensitivity without such a generic grounding can lead to the detrimental consequences of the 'symbolic violence' inflicted when it is implied that every decision has to be treated on a one-off basis; that (e.g.) a prostate cancer screening decision has no connection with an atrial fibrillation treatment one; and that general decisional empowerment is not possible.

1. The Orthodox Approach to Decision Aiding and Evaluation of Decision Quality

We can make this point in a specific way by referring to the evaluation of the aids being produced by Karen Sepucha and colleagues. While these aids contain both knowledge and goals/values components, only the knowledge score is available at an individual level, since the values component of quality is addressed only *ex post*, at a group level, and in terms of the relationship between goals and eventual actions (group level concordance). The recent herniated disk decision aid study provides a good example of what is advanced as a decision quality instrument, but at the individual level reduces to a measure of the knowledge possessed by the patient - after administration of the aid [5]. This is naturally the knowledge in the aid necessary for the choice to be regarded as 'informed'. The mean knowledge score from the patients who viewed the decision aid was used to set a 55% threshold for 'informed'.

The argument is essentially circular, but the issue for us is not whether a patient's information is incorrect, while being perceived to be correct. The issue is whether showing that it is incorrect and attempting to correct the misperception by providing the correct information will constitute symbolic violence, without leading to a *better* decision, as opposed to (possibly) an 'informed decision' according to the orthodoxy.

It is important to make clear immediately that we are not arguing against this sort of condition-specific information being made available in a decision aid and making it available in the form it is usually provided. Indeed we are in favour of making it available on an opt-in basis, probably via links, and possibly even with some weak nudging towards consulting it. We embed our decision aid, based on Multi-Criteria Decision Analysis, (MCDA) in a wider program, MyDecisionSuite, which offers many opt-in customisation possibilities as well as the personalisation for the aid itself [6,7]. We are arguing against any implication that consulting information, retaining it, and attempting to synthesise it with personal preferences, are *necessary* conditions of a good decision, let alone the sufficient conditions implied by prominent decision quality measures.

In our alternative, information essential to a good decision *is* present in the aid, but it is present in a matrix of option performance rates on multiple criteria. This matrix format is familiar to all those possessing the generic decision literacy that enables them to engage with product and service comparison websites. Even then the information matrix is made available only on an opt-in basis, because we do not want to imply that consulting it, and processing it in a way usually referred to as 'making up one's mind', will lead to a better decision. We remain largely agnostic on that, in the same way we remain agnostic whether a decision informed in the orthodox way will produce a better decision – unless it is assessed by a tautologous outcome measure, that is, one using an individual's score on a knowledge/information test as the measure of decision quality. In order to avoid abdicating from the challenge of measuring decision quality within person-centred care we have offered MyDecisionQuality as a self-reported dually-personalised measure [8].

2. Recognising and Supporting Generic Decision Literacy

This generic decision literacy comes in the form of the ability to access and use the decision-relevant resources provided for many consumer services and products on comparison websites and magazines. The methodology on these sites is almost always the simple form of multi criteria/attribute analysis in which the product's ratings on

multiple criteria are combined with criterion weights (supplied by the site) to produce scores and 'best buys' and 'good value for money' verdicts. A large proportion of the population is familiar with this framework and language, its widespread commercial use and popularity of associated sites (e.g. comparethemarket.com) providing the most convincing evidence of this. Over 80% of consumers are reported to have consulted a comparison website in 2010, so the number is likely to be even higher now [9].

In Figure 1 (bottom panel) we enter the ratings for three anonymised free standing washer-dryers that appeared in a recent Which (UK) consumer magazine report on 16 such appliances. Five criteria were rated and weighted to arrive at the overall score. Price was listed separately and not weighted, leaving that trade-off to the consumer.



Figure 1. Ratings, Weightings, and Scores for three anonymised Washer-Dryers from a consumer magazine report re-presented in MCDA format

We do not endorse the particular framing (criterion selection and weightings) and use it only as an example of the sort of content presented in such comparative reports.

The Scores are the expected value of the Ratings and Weightings. Amid all the attempts to improve decision making and information communication, a central concept - expected value - has not received the attention needed even if the objective is to argue against it. We attribute this to the overarching reluctance to address the question of how information should be synthesised with preferences in any explicit way. Such an approach represents a form of reverse symbolic violence, implying that a proper person possesses high quality synthesising ability as an intuitive competence.

While these comparison sites increasingly include ratings and scores for medical devices and health products apps, they avoid evaluations of healthcare options that would involve weightings for criteria such as length of life. That is what our alternative approach, where the options become ones such as lifestyle change, medications and surgery and the attributes ones such as quantity and quality of life and treatment burden. While suggesting that health care decisions may be appropriately approached in the same way as buying a washer-dryer will be surprising if not appalling to some, there are three very good reasons for this extension to healthcare. (It is hopefully clear why the example must not be a healthcare one.)

Since it recognises and exploits a widely possessed type of generic literacy, the alternative not only has less potential to produce symbolic violence but simultaneously greater potential to empower the person. Such empowerment is a precondition of the person owning the decision (whether or not it is in some way shared), which increases the likelihood that the option decided upon will be adhered to subsequently. Whether there is greater concordance in relation to that chosen option is an open question. This will be determined by many things including the clinician's attitude and commitment to person-centred care, as well as quality of both the aid and the discourse surrounding it.

The orthodox approach cannot deliver person-centred care. In person-centred healthcare the relative importance of the considerations that matter to the person in their life is elicited and combined, at the point of decision, with the best estimates available on the performance of the available options on those criteria. This integration is performed in an explicit way which can be communicated to the person. Any prior comparative option evaluations, such as those that constitute the conventional 'evidence base' cannot be part of this process. The ethics of transparent person-centred care require 'evidence base' to be reconceptualised as the unsynthesised matrix of option performance rates for the person-important criteria mapped against the person's criterion preferences [10]. Our approach is therefore not only compatible with person-centred healthcare, it is actually the only way we can see transparent and direct decision support for it being delivered.

Emphasising the generic character of all healthcare decisions enables the individual to visualise any healthcare decision, whatever the condition (or set of conditions) in the same way, rather than it being implied that they need to know a lot about their breast or prostate cancer or whatever. They can then exploit their social and cultural capital which exists because their friends and contacts 'speak the same language' at a decision level. Irrespective of the biological specifics. And that generic competence extend through the life course, so that a sequence of decisions about contraception, birthing technique, and menopause management, as well as any morbidities that arise in the life course, can all be thought of and discussed socially within the same graphic structure.

Professionals already possess this generic decision literacy, so the task should be the simple one of recognising that it should be applied to their area of professional expertise, not just in their domestic life as a consumer. This does not mean writing off their other 'knowledge capital', but it does mean complementing it in order to engage with persons who do not possess it and are at risk of symbolic violence.

3. Reflections

While our focus is on the micro and meso levels, we can speculate about the wider systemic origins of the focus on this particular type of functional health literacy, rather than generic decision literacy. Among the most important macro origins would seem to be the demands for methodological rigour in studies used to justify policy level decisions with financial implications, such as on drug reimbursement or decision aid provision. The dually-personalised measures appropriate for person-centred care do not provide 'hard' criteria, able to be aggregated for groups. Possession, or not, of a proposed set of essential facts, especially about the improvements offered by a new drug or device, is eminently fit for purpose, *given this purpose*. But we question who should define what and how much information is important in person-centred care [11] and sug-

gest reconceptualising the person - previously known as patient [12] - as a researcher engaged in an n-of-1 study for optimal health behaviour choices [10].

Health informaticians interested in supporting person-centred decision making and care at all points in patient pathways, including health records and decision aids, need to acknowledge, accept, accommodate, and adopt MCDA-based approaches to transparently document, support, and evaluate healthcare decisions.

References

- [1] N.R.Adkins, C. Corus. Health literacy for improved health outcomes: Effective capital in the marketplace. *Journal of Consumer Affairs* **43** (2009) 199–222.
- [2] K.Sørensen, S. van den Brouke, J. Fullam, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* **12** (2012) 80.
- [3] G. Elwyn, A.M. O'Connor, C. Bennett, et al. Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PLoS One* **4** (2009) e4705.
- [4] N. Joseph-Williams, G. Elwyn, A. Edwards. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counselling* **94** (2014) 291–309.
- [5] K.R. Sepucha, S. Feibelmann, W.A. Abdu, et al. Psychometric evaluation of a decision quality instrument for treatment of lumbar herniated disc. *Spine* **37** (2012) 1609–16.
- [6] J. Dowie, M.K. Kaltoft, G. Salkeld, M. Cunich. Towards generic online multicriteria decision support in patient-centred health care. *Health Expectations* (2013) online: 02.08.13 doi: 10.1111/hex.12111
- [7] Ø. Eiring, L. Slaughter. An assessment of the potential for personalization in patient decision aids. *Electronic Healthcare Lecture Notes Institute for Computer Science Social Informatics and Telecommunication Engineering* **91** (2012) 51–7.
- [8] M.K. Kaltoft, M. Cunich, G. Salkeld, J. Dowie. Assessing decision quality in patient-centred care requires a preference-sensitive measure. *Journal of Health Services Research and Policy* **19** (2014) 110–7 online first 12.12.13.
- [9] eDigitalResearch. *Comparing comparison sites: a report for Consumer Focus*. Southampton; 2012.
- [10] M.K. Kaltoft, J.B. Nielsen, G. Salkeld, J. Dowie. Increasing user involvement in health care and health research simultaneously: A proto-protocol for “Person-as-Researcher” and online decision support tools. *JMIR Research Protocols* **3** (2014) e61.
- [11] M.K. Kaltoft, J.B. Nielsen, G. Salkeld G, J. Dowie. Who should decide how much and what information is important in person-centred care. *Journal of Health Services Research and Policy* (2015) online first (doi:10.1177/1355819614567911).
- [12] J.A.M. Kremer, M van der Eijk, J.W.M. Aarts, B.R. Bloem. The Individual Formerly Known As Patient, TIFKAP. *Minerva Medica* **102** (2011) 505.