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Bridging the discursive gap between lay and medical discourse in care coordination

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Abstract For older people with multiple chronic co-morbidities, strategies to coordinate care depend heavily on information exchange. We analyse the information-sharing difficulties arising from differences between patients' oral narratives and medical sense-making; and whether a modified form of 'narrative medicine' might mitigate them. We systematically compared 66 general practice patients' own narratives of their health problems and care with the contents of their clinical records. Data were collected in England during 2012–13. Patients' narratives differed from the accounts in their medical record, especially the summary, regarding mobility, falls, mental health, physical frailty and its consequences for accessing care. Parts of patients' viewpoints were never formally encoded, parts were lost when clinicians de-coded it, parts supplemented, and sometimes the whole narrative was re-framed. These discrepancies appeared to restrict the patient record's utility even for GPs for the purposes of risk stratification, case management, knowing what other caregivers were doing, and coordinating care. The findings suggest combining the encoding/decoding theory of communication with inter-subjectivity and intentionality theories as sequential, complementary elements of an explanation of how patients communicate with clinicians. A revised form of narrative medicine might mitigate the discursive gap and its consequences for care coordination.

Keywords: care coordination, informational continuity of care, general practice, England, electronic patient record, patient discourse, narrative medicine

Continuity of care, information and discourses

Care coordination across occupational and organisational boundaries is an important mediator of healthcare outcomes for older people with multiple chronic co-morbidities (Nolte 2012, Parker *et al.* 2011). Patients experience effective coordination as four kinds of continuity of care: relational (the affiliation, responsibility and trust particularly valued by older people) (Parker *et al.* 2011), cross-sectional (holistic care with flexible linkages), longitudinal (continuity over

time) and informational (relevant information is promptly available to other providers) (Reid *et al.* 2002, Ridd *et al.* 2009, Saultz 2003). Various mechanisms facilitate care coordination (Huntley *et al.* 2014, Sheaff *et al.* 2015) and the corresponding clinical outcomes (Burt *et al.* 2004, Gray *et al.* 2003, Olola *et al.* 2011) but all depend upon information transfer and use (Berg 1999, Saultz 2003, Wholey *et al.* 2014). Since Goffman (1959), sociology has possessed rich empirical and theoretical accounts of the discursive gaps between patients and clinicians. Comparing patients' narratives with their clinical records, this article suggests how communication theory can be used to relate these discursive gaps to the non-transfer of information and preferences, then to practical consequences for care coordination. We consider whether a modified form of narrative medicine might mitigate some of these consequences. Whilst we report English NHS experience, these matters concern all health systems attempting to coordinate care more effectively, for example, in the USA, by establishing primary care medical homes.

When patients have complex healthcare needs their care is typically coordinated through three types of interlocking networks (Brand *et al.* 2004, Crooks and Agarwal 2008, Tarrant *et al.* 2015, Wholey *et al.* 2014): the patient's informal support network (family members, friends, volunteers, etc.); the staff or team(s) within each organisation providing care; and an inter-organisational 'referral network' (Southon *et al.* 2005) with its pooled resources. The information transferred from patient to doctor, and how medical records record it, affect what care the patient receives and its coordination (Peikes *et al.* 2009), which requires both the communication of information and its consistency across these networks. However patients' and clinical discourses interpret and frame the patient's health problems differently. This 'frame conflict' (Cordella 2004) has been conceptualised as a difference between what the patient wants and what the doctor offers (Freidson 1984); between patient-centred and illness-centred (Meeuwesen *et al.* 1991) or (for older patients) medical and 'geriatrics' perspectives (Melzer *et al.* 2015); between 'subjective, phenomenally oriented information' and 'evidence-based practice' (Kovarsky 2008) or between 'everyday' and 'institutional' talk (Cordella 2004). Clinicians also often think in a narrative way, but one which sees the patient as 'a page from the book of nature, a text to be read' (Walsh 2004) as clues to diagnostic hypotheses (Gill *et al.* 2010) and 'what is wrong with the body' (Cassell 1999), rather than as a personal, experiential narrative reflecting the patient's 'life-world' (Mishler 1984), that is, the patient's contextualised experience of illness (Greenhalgh 1999), its impacts on her everyday life, and her preferences, feelings and beliefs about her illness or treatment (Elkan *et al.* 2001).

Three main kinds of communication theory, sometimes represented as alternatives (Krauss and Fussell 1996), attempt to conceptualise this frame conflict. Encoder-decoder models focus on information and knowledge transfer (Hall 1980), intentionality-based models on the purposive character of 'speech acts' (Austin 1962, David *et al.* 2009) and 'intersubjectivity' models on whether shared understanding results (Schegloff 1992). Encoder-decoder models assume that practically-oriented communication requires, in clinical encounters, that:

1. A patient formulates ('encodes') an account of her recent health 'career', problems and care needs.
2. She narrates ('transmits') the encoded message to a clinician, who;
3. recognises ('decodes') it (Cassell 1999) in terms of his own clinical discourse (Crooks and Agarwal 2008; Haggerty *et al.* 2003).

By 'patient narrative' we mean patients' narratives about their illness (Hydén 1997). 'Narrative' – as opposed to 'story' – connotes a putatively factual account with low emotional loading (Hovey and Paul 2007), not 'illness as narrative' or as part of a patient's identity (Bury 2001, Riessman 2015). Patients encode their narrative informally (Parker *et al.* 2011), often attaching importance to relational continuity, longitudinal continuity and adequate time to

voice their concerns (Salisbury *et al.* 2011). Wishing to retain some control (Elias and Lowton 2014), older patients may use impression management (Goffman 1959), 'frontload' diagnostic and therapeutic suggestions to clinicians (Greenhalgh and Hurwitz 1999), try to deflect certain interpretations of their health problem (Gill *et al.* 2010), and not seek help for what they regard as normal effects of ageing (Venn and Arber 2012, Elias and Lowton 2014).

In contrast, health workers typically use a clinical, or sometimes hybrid clinical-managerial, discourse of which the patient's clinical record, both on paper (Berg 1999) and electronic, is an important medium. The electronic patient record (EPR) documents and is a means of organising everyday work-routines, particularly patient registration, recall and review (Greenhalgh *et al.* 2009, Swinglehurst *et al.* 2012), and quality improvement. But it also selectively documents what clinicians and managers think is important, privileging particular sources (Berg 1999; Timmermans and Berg 1997), rationalities and 'one language system over equally plausible others' (Bar-Lev 2015: 405). Standardised, protocolised patterns of treatment require standardisation of diagnostic categories and coding, treatment descriptions and definitions, clinical measurements and patient identifiers (Timmermans and Berg 2003; Timmermans and Kolker 2004). Using the medical record is thus a 'moulding process in which the patient and his situation are reconstructed to render them manageable within existing agency routines' (Berg 1998: 399). The EPR can marginalise aspects of care which lie beyond a biomedical focus or contractual requirements (in NHS general practice, the quality outcomes framework (QOF; NHS England, BMA and NHS Employers 2014)), side-lining contextual material and reinforcing separate disease categories (Swinglehurst *et al.* 2012; Walsh 2004). Much information which might be important for determining care is also contained in free text and often difficult to retrieve (Ford *et al.* 2013).

Decoding a patient's narrative involves translating across the differences between the patient's discourse and clinical discourse, each discourse being defined by its characteristic vocabulary, idioms, concepts, implicit assumptions and logic (Silva *et al.* 2011). Decoding involves clinicians discounting seemingly irrelevant, unreliable or inconsistent assertions in a patient's narrative (Hydén 1997; Mishler 1984), supplementing what remains with their own observations and the patient's responses to their questions, and finally categorising and re-framing the resulting information in terms of their own diagnostic categories, empirical assumptions, and norms of good care. The decoded information can then be stored either in the clinician's mind (which does not necessarily mean it will be lost) or, more selectively, through record-keeping. Indeed, clinicians' 'sense-making' (Gill *et al.* 2010) is more a 're-coding' than 'decoding'. Information or other content may be lost, added or distorted; and when later retrieved by the same or other clinicians, the medical record's contents do not necessarily influence clinical practice in the ways the encoder intended (Lang *et al.* 2007). Often, the patient's discourse is then translated in turn between further different clinical discourses corresponding to, say, different professions.

Research questions

Few studies report the consequences of frame conflicts for care coordination and continuity. Most studies of care coordination and continuity focus on concepts (e.g. Gray *et al.* 2003), definitions (e.g. Reid *et al.* 2002), measurement (e.g. Ahgren and Axelsson 2005), and the effects of organisational and management changes (e.g. de Bruin *et al.* 2012). Conversation analysis in these contexts focuses (Pilnick *et al.* 2009) on the dynamics of particular consultations. In contrast, this article analyses what information was changed or lost in communication between clinicians and a group of frail older patients in England, and some implications for care coordination and continuity. We ask:

1. What differences in content were found between patients' and clinicians' discourses, regarding priorities and continuities of care for these patients?
2. What consequences ensued for continuity of care?
3. What implications follow, for explanations of patient-clinician communication, and for clinical practice?

Methods

Design

To answer the first question required analysing their 'frame conflicts' by comparing instances of patient narrative with instances of clinician discourse, above all the amalgam of clinician discourses which the EPR contains. We therefore systematically compared the personal narratives of older patients who had complex chronic care needs with what was documented in their general practice EPRs and reported orally by healthcare professionals caring for them (Kovarsky 2008). We then traced how the mismatches related to the wider care process within which the information exchange was embedded, answering the second question. Comparing these findings with the aforementioned communication theories addressed the third question.

Setting and sample

Five English clinical care groups, a maximum-variety sample of different organisational configurations, were chosen as part of a larger study of continuity of care (Sheaff *et al.* 2015). Nine GP surgeries in them recruited a purposive sample of patients aged 65 and over with at least two (specified) chronic conditions, who had received care in the previous year from at least two separate healthcare organisations, and who were living in their own home or with their family.

Before we met any patients it became obvious that EPRs provided an often partial view of service provision. General practices found it challenging to draw a sample of patients receiving care from multiple providers, and had to rely more on practitioner knowledge than interrogating the EPR. This individual knowledge produced an appropriate sample. With a mean age of 78, these often frail patients typically reported four chronic health problems, most often heart disease, arthritis, diabetes and gastroenterological conditions. 62 per cent had experienced a major change in their health or personal circumstances in the last year.

Data collection

We interviewed 66 patients between May 2012 and November 2013. These in-depth, semi-structured interviews were recorded and transcribed verbatim. They covered patients' health and care needs, and how they were met, probing issues which earlier research (cited above) identifies as relevant to care coordination.

The contents of the patients' EPRs for the year before interview were extracted using a standard pro-forma. It covered direct encounters between the practice and the patient (e.g. appointments, home visits, phone calls), appointments with other services, and care coordination when the patient was not present (e.g. requests to other providers for information or advice, multidisciplinary team meetings). Data collection focused on the 'case summary' (the overview of past and present conditions), consultation notes and clinical letters. Again we focused on issues likely to support or inhibit care coordination, including sources and forms of communication, what information was recorded and transferred, and its degree of contextualisation.

Analysis

Data from both sources were coded and analysed thematically and iteratively. Two researchers checked for similarity of understanding and consistent coding, making constant-comparisons (Glaser and Strauss 1967) between the framework and patterns emerging from the data. We categorised the data within a theoretical framework that reflected the dimensions of continuity of care and of care coordination mentioned above, then systematically compared the contents of the narratives and the patient records to reveal whether, or in what ways, information relevant to care coordination was supplemented, re-framed, or according to patients lost, as clinicians decoded patients' narratives. We counted the instances of such information available from the patients but not their records, and vice versa. In reporting the practical implications of those differences we took the patient record as evidence of subsequent activity or its absence. These methods are limited in that we can only report what the patient records stated rather than what unwritten information clinicians also remembered about individual patients, and during interviews a patient may, as explained above, misremember or re-frame events and information when recalling them. Together, these limitations raised the question of whether to privilege one data source as veridical when the two conflicted. We deliberately avoided that. We made no assumptions about the legitimacy of patients' or carers' demands for care, or of the clinicians' responses. Our focus was informational and discursive continuity.

As NHS ethical approval (reference: 10/H0206/71) for this study stipulated, all data are pseudonymised below.

Findings

Decoding patients' narratives

Patients' health status and access to care The EPR, especially the case summary, reported fewer mobility, falls or fear of falling, and even mental health, problems than patients did (Table 1 summarises).

Patients linked physical frailty to problems accessing care. Sixty five per cent of them reported difficulty walking outside, including 12 per cent reporting that they could not walk at

Table 1 *Frequency of interview, electronic patient record (EPR) and EPR case summary mentions of health and healthcare issues*

<i>Issue</i>	<i>Interview (%)</i>	<i>EPR (%)</i>	<i>EPR case summary (%)</i>
Restricted mobility	65	44	9
Mental health problems	27	23	19
Falls (including risk of falling)	38	34	5
Pain	57	85	19
Care plan	10	25 ¹	6 ²
Secondary Care	24	19	20
Community health services	17	14	0
Social care involvement	32	3	3

¹Combined treatment plans and overall care plans. ²All in one study site.

all and 6 per cent who walked only with help. Fifty three per cent said that they could not drive, mainly because of poor health. EPR case summaries labelled only 9 per cent as housebound, but a free-text search identified mobility problems in another 35 per cent. Patients' narratives revealed how mobility constrained access to services, reduced continuity of care and could leave them feeling unsupported, isolated and stressed. One patient, a walking aid user, described herself as being unable to walk outside the home 'except a few steps really':

There's, obviously there's the physical disability of limited mobility, that is a real problem because I used to, I've never been a driver because I've had sight problems, and I used to use public transport everywhere [...] but I can't do that now [...] I can't get to the bus stop without a taxi [...] I feel myself stuck at home when I used to be able to go out and about (Patient A)

Even visits to the GP surgery meant a 'struggle to get up and down the ramp'. This was compounded by communication problems and depression, meaning that she 'didn't trust the system any more really' and felt that if she 'came here [GP's surgery] about anything I really wouldn't get much help, that has been the pattern recently, in the last few years'. In her record the only recent explicit reference to her mobility problems was in a letter from a hospital.

Other physical problems such as incontinence, and mental health issues such as anxiety and dementia, also confined patients to home. One patient, again not recorded as being housebound or experiencing mobility problems, said: 'I haven't been outside the door for 12 months because I can't trust myself you see' (Patient B). She was able to maintain relational continuity of care by phone: 'I got a bit concerned because I was ringing up so many times, she [patient's GP] said, "Don't worry about it, just ring"'. Another, recorded as a frequent attender with a care package but not as having mobility problems, described herself as unable to attend the surgery or 'see the same person' and was reluctant to rely on the telephone:

It is more difficult by telephone. I have overheard people say it is time wasted if the doctor comes to see you. I feel my care should be worthwhile, but I feel they are in a hurry to get off. You wonder if they are listening to what you say in the end. I feel I have to deal with it on my own. (Patient C)

Her confidence had diminished because she didn't 'get the chance to see the same doctor again – they are not there or they are too busy'.

Conversely, patients were frequently silent about or normalised their poor mental health (Dew *et al.* 2007, Knowles *et al.* 2015). One patient with chronic schizophrenia and another with hypomania, for instance, did not mention their mental health during interview other than difficulties sleeping. Mental health problems (mostly depression, Alzheimer's, memory loss, panic disorder, anxiety) were mentioned in both the patient's narrative and EPR for only 12 per cent of patients, although another 15 per cent of patient narratives and another 11 per cent of EPRs separately mentioned them. Yet only one per cent of recorded transactions originated from mental health services. Only two per cent of recorded referrals were to them. Patients were not necessarily failing to access these services, but communication with GPs about it remained slight. Similarly, 38 per cent of patients talked about falls in interview and 34 per cent of EPRs referred to falls, but only three patients' case summaries (5%) mentioned them. Indicators of frailty mostly emerged only from a detailed free-text enquiry.

Pain and its management Patients' accounts placed greater emphasis on pain and its consequences than the EPR case summary, did. Many patients (67%) mentioned pain at least once

in interview and it was noted in nearly all (85%) of medical records. Fifty two per cent mentioned pain both in interview with us and, as their medical records recorded, in consultations with clinicians. Yet patients' case summaries recorded pain much less often (19%) and some patients felt it was not taken seriously. Patients often felt that being 'pinned in pain' (PI10) (attributed predominantly to back, leg and joint problems and conditions such as arthritis, polymyalgia and osteoporosis) could be all-consuming and life-limiting: 'I mean, I was crawling here on my hands and knees, the pain was so awful' (Patient D).

Yet they also felt it was difficult to get their GP to listen or to get a diagnosis: 'Well, it was, take some painkillers, really, not interested to be honest' (Patient E). For one patient, only a loss of self-control had precipitated action:

[O]ver the years the leg has been painful, over the last three years it's got increasingly painful. (. . .) Anyway, to get to see a consultant I had to go and sit in my doctor's surgery and cry to him. I did, I sat there and cried and I said to him, 'I can't put up with this pain any longer'. (Patient F)

Patients' perception that their pain was not taken seriously enough was also inimical to relational continuity and trust, to the extent that some withdrew from medical encounters: 'I thought you're not going to listen, what's the point in talking to you? I'm not stupid, what's the point if the doctor won't listen?' (Patient G). The omission of pain from the case summary is noteworthy given its centrality to chronic conditions and since those who express their unhappiness through pain (or depression) (Bower *et al.* 2011) are likely to be poor co-producers of health and report less satisfaction with primary care services (Paddison and Saunders 2015).

Consequences for continuity

Most, though not all, patients had a care coordinator, although that did not necessarily result in them accessing services. Particular general practices and GPs made real efforts to sustain patient-centred care coordination. By the criteria of initiating additional care or referrals, or of patients approaching them rather than other providers, we found GPs acting as main care coordinator for 53 per cent of patients. Secondary care was the only other substantial source of care coordination (for 8%). Twenty eight per cent of patients had no identifiable care co-ordinator. Levels of community support, onward referral, home visits and care coordination by GPs appeared to be higher when the practice operated patient lists or when the patient predominantly saw the same doctor, suggesting that longitudinal continuity of care facilitated cross-sectional continuity.

These efforts did not always sustain access to further services. Some patients felt that community services, especially district nursing, were quick to suspend home visits by interpreting the term 'housebound' strictly, as 'never leaves home unaided', and treating conditions as acute and discrete rather than chronic and connected. One of the few patients whose EPR did categorise her as housebound, a wheelchair user describing herself as having 'no balance at all', had district nursing services withdrawn:

I used to have a district nurse when I first came out of hospital, a year last March, and she used to come in every day because I was special vancomycin or special treatment for the MRSA. And they carried on doing my site, and that was for about six weeks. And then my daughter had a very special birthday, [. . .] she booked a wheelchair and everything for me, so I could go from wheelchair to wheelchair. And I was looked after very well and then eventually brought home. But because I could get out –

I: You were discharged from the district nurse team?

‘Yes’. (Patient H)

This case illustrated how community health services might also not decode a patient’s narrative as she intended.

Care reviews Care reviews were far from universal, and those that did occur often reviewed a particular illness rather than the patient’s health as a whole. Patients valued regular reviews of their care, 77 per cent regarding reviews as important because they provided reassurance. Notwithstanding their problems with mobility, pain and access to non-domiciliary services, 44 per cent of patients said their care was ‘never’ reviewed. Another 17 per cent said it was reviewed annually. Patients distinguished between GP-initiated overviews and what they saw as NHS ‘box ticking’ (Patient I), referring to the recent proliferation of nurse-led reviews focusing on specific chronic diseases, each with their own template (Swinglehurst *et al.* 2012). GPs also felt this distinction:

We need to take a more doctor-centred approach to chronic disease management. The nurses are good but if, for example, they follow the diabetic protocol – such patients will inevitably also be hypertensive and have chronic artery disease [...] A GP appointment may not be so cuddly or client friendly but it does deal with the whole smorgasbord. (GP).

Although patients valued overall care reviews, GP records incorporated care plans in 25 per cent of cases, and most of these might more correctly be designated treatment plans (written by community nursing teams rather than addressing all needs together). Even they were absent in three practices. Only 10 per cent of study patients were aware of having a care plan.

Patients asserted that practice policies discouraged them from bringing more than one problem to consultations. (One would expect that policy to reduce cross-sectional continuity of care.) One patient thought this was why his diabetes had long remained undiagnosed:

you are treated as two separate people: the person that’s got the neurological problem and the person that’s got everything else that’s wrong with them. And never the twain shall meet. There is no understanding, interest. And many times I have said to both sides, ‘I want to be treated as one patient, not as two separate patients’. (Patient J)

When consultations were hard to get, patients had to decide which health issue to prioritise:

for older people [...] you seem to collect a myriad of problems like a shopping list and they are all quite relevant, but you know if you were to go back for each one you would never be away from the doctors. I often think I wish there were somewhere I could go where you could go to talk to somebody about all these different things, which may be important but may not be important. (Patient K)

On the GPs’ side, one recorded ‘unrealistic expectations about what can be safely managed in ten minutes’. Furthermore, the EPRs revealed that GPs did recognise complex needs and often relaxed the rule. Fifty nine per cent of study patients had brought more than one problem to at least one consultation. Forty three per cent of patients were reviewed *in absentia*.

Relational continuity Workload pressures were a barrier to maintaining relational continuity of care. Patients liked the idea of having one’s own GP (as Sans-Corrales *et al.* 2006 corroborate)

because they felt it important that someone was responsible for coordinating their care as a whole. Many patients reported difficulties seeing the same GP at successive consultations. Then, their desire to access help urgently often took precedence over their desire for relational continuity:

You have to sort of take who you get because trying to get one particular doctor is – you could wait for days or weeks. (Patient L)

This discontinuity did not necessarily cause poor-quality interactions with the other doctors but patients recognised the shortfall:

I have to say they were all absolutely gorgeous but there was no continuity. I saw a different person every time I went. (Patient M)

However a minority of patients focused on whether the GPs knew them (i.e. had the necessary information to hand) rather than whether they knew the GP.

The EPRs corroborated this lack of longitudinal continuity. They showed that patients had on average (mode) seen four GPs in the preceding year (range 1–10). Nevertheless 55 per cent saw the same GP on more than half their practice encounters and so might be considered *de facto* to have a ‘designated’ GP.

Informational Continuity Co-ordination was hampered by lack of information about other care providers’ involvement. Although information about secondary care represented 19 per cent of all recorded transactions and those with community health services (CHS) 14 per cent, we generally had to infer information about other services’ involvement from the free text in the EPR. CHS had read/write access to GP records in only one site. As noted, such communications were uncommon for mental health. No EPR entries in our sample originated from social services and only three per cent of referrals were to them, but at interview 14 per cent of our patients mentioned their current social care package and another 18 per cent home equipment and adaptations. At least a quarter of patients in each study site recounted examples where information about their diagnosis, history, or treatment had not passed between providers. Patients said that they themselves were often the conduit of information, despite suffering from illness or failing memory; but were also often disbelieved when their accounts conflicted with the medical record. To avoid confusion several carried their own notes on past treatments, current medication and key personnel. Letters to them were not always intelligible: ‘They use words I don’t understand’ (Patient N) or ‘give you little information and leave you to report on things’ but as one patient with mental health problems stressed one ‘can’t always do that’ (Patient O).

Conclusions

Frame conflict, care coordination and continuity

In summary, patient narratives emphasised certain main impacts on everyday life and health-care - mobility, pain and risk of falls – which were not well captured by the EPR, particularly the case summary (Table 1). Compared with patients’ narratives, the case summaries also appeared to under-record patients’ difficulties in accessing services and maintaining contact over time. Parts of these patients’ narratives were never formally encoded, parts were lost when clinicians de-coded them, and sometimes the whole was supplemented and re-framed. Contextual information was also typically sparse, with little acknowledgement of informal carers, functional impairments or whether a patient lived alone. Patients’ narratives expressed

their associated feelings of vulnerability and dis-empowerment, but these points were often absent from the formal record. Rather than ‘affording’ (Petракaki *et al.* 2016) the recording and use of patient narratives, existing EPRs tended to constrain it. In these senses we found a lack of agreement (‘inter-subjectivity’) between patient and clinician about the priority and everyday practical significance attaching to different health issues. Patients perceived this lack of ‘hearership’ (Swinglehurst *et al.* 2011) as ‘the doctor not listening’ but selective encoding by the patient (based on available time) contributed. Insofar as patients’ recall was mistaken, biased or re-framed (which our methods did not allow us to assess), these discrepancies may sometimes have reflected patients’ perceptions rather than fact. Nevertheless they have implications for care coordination.

Patients’ narratives and other parts of the clinical records suggested that many of our patients had restricted ability to coordinate their own care, yet the EPRs did not help identify that point in the case summary. The substantive and discursive differences between the patients’ narratives and the contents of their medical records did not stop GPs trying to coordinate these patients’ care to some extent. Nevertheless, these patients appeared often to lack holistic reviews of their health, health care and care plans. The case summary’s failure to record whether the patient was housebound had consequences for access to domiciliary care. The omission of pain was important given its centrality to chronic conditions and self-care. References to care or treatment plans were frequent in the patients’ records but seldom captured holistic care needs or involved the patient as co-producer. Except for hospital referrals, EPRs held little explicit information on other services’ involvement. The EPR’s focus, particularly in the case summary, on clinical codes (in England, Read codes) and its missing contents also appeared to restrict its usefulness to GPs for the purposes of risk stratification, selecting patients for case management, and knowing what other care givers were doing.

The contents of the EPR reflected existing work-routines and the resources for them, for example: access to GP appointments; length of appointment; one-problem-per-appointment rules; the ways in which GPs were rostered to clinics, appointments and therefore patients; and the increasing division of clinical labour between doctors, nurses, healthcare assistants and other workers. Reinforced by heavy and increasing workloads (Hobbs *et al.* 2016) these working routines and resources were adapted to handle large numbers of short-episode, single-problem cases (transient illnesses, minor and moderately severe injuries, preventive interventions) with the GP undertaking care coordination as required (often, none). NHS management and payment systems also still reflect this pattern, emphasising large numbers of short appointments and GP productivity. Patients’ narratives suggested how this model of care conflicts with the requirements of caring for people with long term chronic conditions, particularly the needs of the frail elderly prone to exacerbations.

Our findings warn against assuming simplistically that universal adoption of EPRs, at least in their present state, will alone achieve informational continuity and facilitate care coordination between organisations (Adams 2016). At worst, present-day EPRs distract the clinician’s attention from the patient during consultations, reducing clinician responsiveness to the patient’s narrative (Håland 2012, Jones 2009, Lown and Rodriguez 2012). They require considerable modification to accommodate person-related information (Schrans *et al.* 2016). Also our findings warn against simplistically assuming that patients always remember events and information without mistakes, bias or re-framing.

From encoding to care

These findings suggest that the encoding/decoding, inter-subjectivity and intentionality models offer sequential and complementary, not alternative, accounts of communication between patients and clinicians. Figure 1 conceptually combines them.

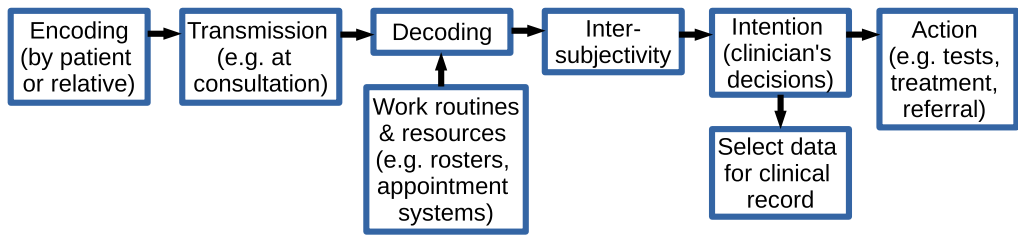


Figure 1 *Combined Model: Stages of verbal communication*

Each step is performative, and the consequences of the whole process are emergent. We have reported how patients may not (sometimes cannot) encode all they want to say. Hurried appointments may truncate their narrative ('transmission'). Information is lost, added or re-framed during decoding. Clinicians have some discretion about what to write in the clinical record (Jones 2009) and what to keep in their heads. Only a partial inter-subjectivity may result; then, what the clinician intends to do may not match what the patient intended. Finally, the clinician's intentions may not be realised in practice. As explained, the work-routines and resources available to the clinician constrain (moderate) the decoding stage. Even so, this combined model is still simplified by omitting sub-stages nested within each of the main stages in Figure 1, feedback loops (e.g. how patients respond to the clinician's responses to them (Stiles 1989)) and, possibly, other moderators (e.g. language barriers, cultural competence, ethnic cultures; Betancourt 2006, Cordella 2004, Fernandez *et al.* 2004). It focuses on what knowledge is transferred, its mutating content and any resulting action, while still recognising clinicians' power to recode patients' narratives. It now requires further conceptual development and empirical refinement.

Narrative medicine reconsidered

For clinical practice, these findings suggest possible communicational responses to these frame conflicts, and an epistemological response. The concept of 'narrative medicine' formulates how doctors ought (its proponents say) to respond to the 'telling and listening to the stories of illness' (Charon 2001: 1899), and the competences required (Hatem and Rider 2004). Previous discussions of narrative medicine (Charon 2001) and person-centred care (Elkan *et al.* 2001) focus on understanding the patient's health and healthcare needs in the round as an aspect of individual clinicians' competence (Loignon *et al.* 2015), and upon the therapeutic effects of narrativisation (Cepeda *et al.* 2008, Hatem and Rider 2004, Hovey and Paul 2007). Silva *et al.* (2011: 587), for example, advocate a 'Problem delineation, clinical Actions, Choices, Targets' (PACT) model of 'scientific nurturance within clinical practice' which attempts to combine understanding of patients' narratives with evidence based medicine, not least in 'clinically uninteresting' cases. Coiera (2000) presents a technique of seeking 'common ground' in conversations, Ventres (2015) one of examining patients' 'presentations of self'.

Older patients' concerns for relational and longitudinal continuity might be better served by health records which capture the cumulative burden of multiple diseases and the organisational and individual barriers to care, and which therefore more systematically include and exploit documentary and structured text entries (Bleeker *et al.* 2006, Lovis *et al.* 2000).

These communicational implications, and the point that patients do not always remember events and information accurately without bias or re-framing, raise an epistemological question: Can patients' 'subjective' accounts of their 'life-world' and evidence-based practice be combined to their mutual enrichment (Greenhalgh 1999, Silva *et al.* 2011, Timmermans and Almeling 2009), or are the two in practice antithetical (Kovarsky 2008)? In logical terms the

two frames of discourse are complementary, not conflicting, forms of ‘evidence’ because one has an instrumental relationship to the other (Sheaff 1996). Within certain limits, the patient has privileged knowledge, because of its subjectivity, of her desires and needs in everyday life, and ‘the interaction among . . . [its] biologic, psychologic, and social components’ (Smith and Hoppe 1991: 470). Conversely, within its current scientific and practical limitations, evidence-based practice formulates privileged (scientific) knowledge of the means by which clinical practice might satisfy those desires and needs. In epistemological principle, the patient’s narrative supplies the ends (Elkan *et al.* 2001), and evidence based practice the means, in addressing her health problems. Granted, the clinician will sometimes have evidence that a patient’s subjective knowledge about her daily life and needs is corrigible (e.g. if the patient seems cognitively impaired) but since the patient has privileged knowledge, the onus of justification for disregarding her narrative lies *prima facie* with the clinician. In our view the specific contribution – and limitation – of narrative medicine is in eliciting (e.g. through ‘person-centred’ consultations) the patient’s judgement about what ends evidence-based practice should, in her case, serve.

The few empirical studies of narrative medicine focus upon doctors’ responses to suffering, especially in life-threatening illness and terminal care (Cassell 1999). Important as these matters are to patients, they are different foci to that of who will coordinate their care, how that will be achieved, and the effects of chronic illness upon their pain, mobility and capacity for self-care. Narrative medicine brings the quality of doctor-patient relationship into focus, which one would expect to strengthen relational continuity of care. An important future development would be to develop its application to long-term care of multiple chronic conditions, including access to care and inter-organisational care coordination; and the process of care itself. Patients have ongoing conversations with the same or different practitioners, constantly reworking the shared understanding (‘intersubjectivity’) of the patient’s functional problems and personal experiences, medical diagnoses and personal goals; and reworking the associated ‘shared plan’ (how different practitioners should address these goals, and through which evidence-informed interventions). How this all plays out in the medium of the EPR is a key challenge facing the integrated care ‘movement’. The EPR is often seen as a solution to poor coordination or continuity but it remains unclear whether a single vertically and horizontally integrated clinical record (New Zealand model), real-time data-sharing across separate providers, or patient led and ‘owned’ EPR systems (Adams 2016) are this solution and if so, for which contexts. In any event a truly person-centred EPR system will need to make an interpretation of the patient’s narrative, focused upon her functional and social problems and goals, the main driver of care provided by each practitioner involved.

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