From boundary object to boundary subject; the role of the patient in coordination across complex systems of care during hospital discharge

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Abstract

Advocates for patient involvement argue that seeking the active contribution of patients and families in the coordination of care can help mitigate system complexity, and lead to improvements in quality. However, sociological and organisational research has identified barriers to involving patients in care planning, not least the power of, and boundaries between, multiple professional groups. This study draws on literature from Science and Technology Studies (STS) to explore the patients' role in coordinating care across professional-practice boundaries in complex care systems. Findings are drawn from a two-year ethnographic study (including 69 qualitative interviews) of hospital discharge following hip-fracture care, and describe the changing role of the patient as they move out of hospital into community settings. Findings describe how 'the patient' plays a relatively passive role as boundary object while recovering from surgery within hospital, where inter-professional coordination was prescribed by evidence-based guidelines, leaving little space for patient voice. As discharge planning begins, patient involvement is both encouraged and contested by different professional groups, with varying commitment to include patient subjectivities in care. As patients move into home and community

1 settings, they, their families and carers play an increasingly active role in

2 coordination, often in light of perceived gaps in coordination between care

3 providers. This paper argues that whilst the need for patient and carer

4 involvement is becoming increasingly evident, such involvement plays into, and

5 is mediated through, existing relations between professional and practice

6 groups. Patient and carer involvement is therefore not straightforward and

7 should be considered across the health and care systems in order to

8 meaningfully improve care quality.

9

25

1   **Introduction**

2   Research shows that care quality depends on the coordination of many

3   professionals working within and across organisational boundaries (Weinberg et

4   al, 2007; Moore et al., 2003). Although coordinated or integrated care is a

5   longstanding policy concern, the challenge of coordination is increasingly

6   interpreted as rooted in the complexity of care systems (Braithwaite et al, 2017).

7   This view suggests that care is routinely organised through large numbers of

8   heterogeneous groups cooperating in non-linear patterns of interaction, rather

9   than through relatively well-defined, linear pathways. Integral to the sociological

10   analysis of these complex systems is the persistence and influence of social

11   boundaries between interacting groups, and how these exacerbate system

12   complexity   through   complicating   inter-professional   or   organisational

13   interactions.

14

15   In this context, there have been calls for more active patient involvement as a

16   basis for improved cross-boundary coordination (O'Hara and Lawton, 2016;

17   Ellins et al., 2012). Specifically, patients and families are identified as the sole

18   consistent presence across the times, spaces and relationships of complex care

19   systems. This therefore makes them ideally placed to act as the fulcrum around

20   which services are organised, especially for helping to coordinate care across the

21   professional and organisational boundaries that are shown to shape care

22   processes. Drawing on organisational theory, patients and families might be re-

23   cast as 'boundary spanners' (Williams, 2002), given their unique position to

24   manage the interface between different occupations and organisations,

25   especially to support communication and coordination amongst disparate

1   groups. Research shows, for example, patient involvement in care planning and

2   integration can lead to improvements in clinical outcomes and patient

3   experience (Dyrstad et al., 2015; Flink et al., 2012).

4

5   While patients' involvement has a strong normative appeal, a wealth of

6   qualitative and quantitative studies suggest there are enduring limits to patients'

7   ability to adopt a coordinating role (Joseph-Williams et al., 2014). Prioritising

8   patients' subjective experiences stands against dominant biomedical evidence,

9   rooted in objectivity and quantification at the aggregate level; patient views are

10   therefore only partially and problematically incorporated into clinical decision-

11   making (May et al., 2006). Evidence-based medicine - marshalled into healthcare

12   practice through the proliferation of bureaucratic technologies such as clinical

13   guidelines, decision tools, checklists and performance indicators - requires

14   clinical professionals to adopt increasingly standardised practices (Timmermans

15   and Berg, 1997). Standardisation shapes not only the work of individual

16   professionals, but also forms the basis of cross-boundary working, itself

17   dependent on routine and typification. Highlighting this, Allen's work (2014a;

18   2018) identifies the role of 'translational mobilisation'; the transformation of

19   people into organisationally recognised patients, reconciling their divergent

20   needs with systems, resources and care pathways. Clinical work, Allen argues, is

21   increasingly constituted by the efforts of translating patients across parallel

22   bureaucratic systems within and across organisations. As such, the status of

23   patients as both the agents and objects of coordination is far from clear.

24

1   To further explore the role of patients (as agents and objects) in the coordination

2   of care across professional and organisational boundaries we bring together

3   sociological literature on professional and organisational boundaries with

4   Science and Technology Studies (STS) work on boundary objects. That patients

5   themselves could be considered boundary objects has been noted elsewhere, yet

6   the implications of this for the organisation of care have yet to be explored

7   (Nicolini, et al., 2012). The concept of the boundary object provides a basis for

8   exploring how coordination is achieved through contrasting forms of patient

9   objectification across professional and organisational boundaries. Through

10   ethnographic study of hospital discharge, we find that patients' role in the

11   coordination of care shifts from being relatively passive within the tightly

12   organised hospital environment to becoming relatively active as they move out

13   of the hospital into loosely organised community and domestic settings. In doing

14   so, we highlight gaps in current systems of coordination, not straightforwardly

15   addressed through patient involvement. We also extend theoretical study of

16   objects during scientific and professional coordination by outlining how the

17   patient plays a varied role as boundary-object, boundary-subject and boundary

18   spanner, with movement between these different roles reflecting professional

19   and organisational struggles over their care.

20

21   **Boundaries and boundary objects in the coordination of care**

22   Boundaries have been the focus of considerable attention across the social

23   sciences (Lamont and Molnár, 2002). In the field of health and social care,

24   boundaries are often described in relation to the division of expert labour,

25   especially the jurisdictional boundaries within and between professions (Abbott,

1   1988; Waring and Latif, 2017). The sociology of professions identifies how the

2   creation, maintenance and disruption of social boundaries – boundary work – is

3   intrinsic to the constitution of discrete professional jurisdictions within a

4   competitive system of expert labour (Abbott 1988; Gieryn, 1983; Ehrich et al.,

5   2006). Professional boundaries have been shown to cause fissures in patterns of

6   knowledge sharing (Currie et al, 2007), the spread of innovation (Ferlie et al,

7   2005) and care practice (Dixon-Woods, 2010).

8

9   At the meso and micro levels, professional boundaries interact with

10   organisational boundaries, creating divisions between communities of practice

11   (Lave and Wenger, 1991). Within organisational research, boundaries between

12   such professional-practice groupings have been considered around three

13   overlapping domains (Ferlie et al., 2005). First, boundaries of knowledge, with

14   professions defining themselves by specific forms of expertise. This is

15   exemplified by the difference between the hierarchy of bio-medical evidence

16   prioritised in acute medicine, against the deliberative and situated

17   understandings valued in social care (Webb, 2001). Second, boundaries of

18   identity and culture, including the extent to which professional groups value

19   inter-professional decision-making or prioritise patient involvement in their

20   own care (Dent and Whitehead, 2013). And third, boundaries of organisation

21   including the established routines, rules, resources, and divisions of labour

22   present in professional organisations (Timmermans and Berg, 1997).

23

24   From a STS perspective, the boundaries within and between expert groups and

25   their implications for knowledge production have been a central concern. The

boundaries between science and non-science, for example, have provided the impetus for research on 'boundary work' (Gieryn 1983), and of particular relevance to this study, the concept of 'boundary objects'. Star and Griesemer (1989) identify boundary objects as 'things' that have divergent meanings and uses for the different social groups, but which maintain sufficient common identity to provide the basis for collaborative endeavour. Star and Griesemer (1989) identified repositories (library catalogues), ideal types (blueprints), objects with coincidental boundaries (maps) and standardised forms as common objects in scientific enquiry that enables specialist to coordinate their distinct activities.

Qualitative research has elaborated various forms boundary objects can take (Fox, 2011; Swan et al., 2007), the processes by which they foster, or limit, collaboration (Oswick and Robertson, 2009) and the relationship between objects, boundaries and social worlds (Bechky, 2003; Swan et al., 2007). For instance, theories (Fox, 2011), phrases (Brand and Jax, 2007), and practices (Owens, 2015) have all been interpreted as boundary objects with variable implications for collaboration. Within healthcare, Allen's (2009; 2014b) research examines collaboration between professional, managerial and service user groups in the process of developing new care pathways. This finds participants using considerable political and organisational skill to design pathway tools (boundary objects) that afford space to negotiate tensions between professional groups. Keshet et al., (2013) demonstrate how multiple boundary objects allow 'loose collaboration' across the social-structural and epistemic boundaries between alternative and conventional medicine, highlighting in particular the

1   importance of epistemic 'fit' between objects and the wider institutional

2   environment.

3

4   There has been less consideration of how people, or human bodies, act as

5   boundary objects. This is perhaps surprising given the analytic equivalence

6   afforded to human and non-human entities within Actor Network Theory and

7   STS. A notable exception is Mol's (2002) examination of how patients' bodies and

8   diseases are enacted heterogeneously in the everyday performance of cross-

9   disciplinary medical work, with different versions of disease rendered knowable

10   through the application of multiple technologies and fields of medical

11   knowledge. Here, the body acts as a boundary object for professional-practice

12   groups, as their distinct forms of practice 'hang together' through their

13   pluralistic enactment of the body, related to their own technologies and practices

14   of work. Although this demonstrates the essential role of the patient as a central

15   object in coordinating healthcare work, Mol's work focuses on the hospital

16   environment, rather than the contribution of the patient to coordination across

17   complex systems of care.

18

19   It is worth recognising that examining the patient as a boundary object could

20   appear contradictory to the aspirations of the patient involvement movement,

21   i.e. holding patients as passive objects of professional practice. However, as

22   Timmermans and Almeling (2009) argue 'objectification' serves a variety of ends

23   for patients as well as for professionals and organisations. Medical advancement

24   depends upon professional specialisation, increasingly fragmenting the body

25   into constituent elements. This, Timmermans and Almeling (2009) argue, can be

1 experienced as alienating, empowering or restorative, depending on whether the

2 patient feels involved in the care process and/or whether treatments are felt to

3 lead to improved experiences of health and wellbeing. As Cussins (1996)

4 illustrates in the context of infertility treatment, patients may in fact

5 demonstrate agency through participating in self-objectification as they actively

6 seek to improve their chance of successful reproductive outcome. Further

7 discussed by Prentice (2003), professional socialisation involves taking on

8 distinct professional cultural rules on acceptable 'object formation' whilst

9 avoiding problematic 'objectification'.

10

11 This suggests that rather than a clear division between patients as passive

12 objects of care, or patients as active agents, we should instead look for different

13 forms and implications of objectification, especially at the intersection of

14 different professional boundaries, where varying interests, knowledge and

15 practices are involved in the coordination of care. For example, we can identify a

16 comparatively 'narrow' understanding of ailments or body parts fitting with the

17 knowledge of higher status and more specialised medical and surgical groups

18 (Prentice, 2013), and broader or 'holistic' understandings of patients amongst

19 lower status therapists and social care communities (Finlay, 2001). However, the

20 implications of these different care 'objects' on coordination are yet to be

21 considered. This study investigated how professional groups engage in such

22 object formation, to consider the patient's role in coordinating across boundaries

23 in complex care processes.

24

25

1   **Coordinating Hospital discharge**

2   The challenges of coordinating care across professional boundaries is

3   exemplified by hospital discharge; the transfer of care from the hospital to a

4   community setting (Aase et al., 2017; Glasby et al., 2008). The transfer of patients

5   between care settings is widely recognised as a vulnerable and high-risk stage in

6   the patient journey (Forster et al. 2003; Moore, et al., 2003; Kripalani et al.,

7   2007a). Prominent threats to safety including problems with medicine

8   reconciliation, managing wounds and infections, and continuity of care (Burke,

9   2003; Grimes et al., 2008; Kripalani et al., 2007b; Waring et al. 2013). The threats

10   to safe hospital discharge are often rooted in the complexities of coordinating

11   care across professional boundaries. As patients move out of hospital, care

12   responsibilities pass between professional groupings (e.g. hospital clinicians and

13   community social workers), between organisations, (e.g. acute and community

14   hospitals), between care sectors (e.g. health and social care), and between

15   economic sectors, (e.g. from the public to not-for-profit or private sector).

16   Ethnographic research on discharge pathways reveals significant contradictions

17   and limitations in the social organisation of care (Wells, 1997), including conflict

18   between the needs of individual patients and the multiple bureaucratic systems

19   through which their care is organised. Hospital discharge is therefore a critical

20   case to examine the patients' role in coordination across professional boundaries

21   within complex systems of care.

22

23   **Methodology**

24   This paper draws upon the findings of a two-year ethnographic study of the

25   social organisation of hospital discharge. Taking an ethnographic approach

1 allowed for direct observation and 'thick' description of the locally important

2 elements of discharge planning and care transitions, which were interpreted in

3 terms of the social and cultural boundaries that shaped the social organisation of

4 hospital discharge. All relevant ethical approvals were obtained through the UK

5 NREC prior to research commencing.

6

7 The ethnographic study was undertaken in two regional care systems in the

8 English National Health Service (NHS). Each system was organised around a

9 medium-sized English city with a single NHS Trust providing acute care; in

10 excess of 20 NHS primary care providers (General Practitioners); and between

11 two and four community NHS hospitals and rehabilitation services. Each system

12 also involved social care commissioners and providers, in the form of local

13 authority (municipal) 'social services', and a large range of public, private and

14 third sector social care providers.

15

16 Within each of these care systems, the study focused on the discharge of patients

17 receiving inpatient hip replacement surgery and physiotherapy, followed by

18 community-based on-going physiotherapy and other rehabilitation care. Hip

19 fracture was chosen as a condition predominantly affecting frail older people

20 who often have multiple co-morbidities including both physical and cognitive

21 impairment (Giusti, et al., 2011). As such, discharge planning is often complex,

22 involving consideration of past and future long-term health and social care

23 needs. Care for hip fracture patients requires a wide range of acute and

24 community specialists to work in close cooperation (Tierney and Vallis, 1999),

25 including orthopaedic and orthogeriatric medical teams, nursing groups,

1   therapists and social care providers. Readmission rates are relatively high, and

2   previous studies have shown the period following hip fracture present

3   challenges for organising safe and effective ongoing care (O'Cathain, 1994).

4   Finally, hip fracture services in the UK have been subject to national policies to

5   standardise care pathways, including guidelines for multi-disciplinary care and

6   are therefore an appropriate site to investigate coordination across professional-

7   practice groups.

8

9   Data were collected (2011-2013) through qualitative interviews and non-

10   participation observations of discharge planning and care transitions over a two

11   year period. Approximately 120 hours of observations were undertaken over a

12   two year period, focusing on the temporal and spatial organisation of daily work

13   (schedule of ward rounds, meetings, handovers, discharge times); identifying key

14   events and activities (MDTs, drug rounds); identifying key individuals or groups

15   ascribed with knowledge sharing roles (discharge co-ordinators, clinical leads).

16   In addition, semi-structured interviews were carried out with staff (69 staff

17   interviewees across the hip fracture pathway, see table 1). Interviews with staff

18   lasted on average 45 minutes and explored participants' role, the routines and

19   experiences of coordinating with other staff groups, the processes of hospital

20   discharge and perceived risks and challenges. The study also 'followed' the

21   discharge journeys of 17 patients, including interviews at up to three time points

22   (once in hospital and two times up to six week after discharge).

23

24   **INSERT TABLE 1 'Interview respondents' ABOUT HERE**

25

Interpretative qualitative data analysis was undertaken to develop descriptive and contextualised understanding of cross-boundary work and its contribution to discharge. This involved an iterative process of close reading of data, coding, constant comparison, elaboration of emerging themes and re-engaging with wider literature. Themes were developed through first independent open coding by both members of the research team on samples of the data, with initial codes used to code the rest of the data, with additional codes added and refined at regular intervals during the analysis process. As the coding process progressed, thematic categories were identified. While the study was oriented to investigate issues of coordination across boundaries, the current focus on the patients' boundary role emerged only through data collection and analysis, becoming evident in light of limitations of other mechanisms of coordination.

Findings

In both study sites, the work of managing discharge was dispersed across multiple professional and occupational groups **(see Table 2).** Differences in the knowledge, culture and organisation of these professional-practice groups made discharging patients a continual challenge. Commonly discussed boundary challenges included discordant IT systems, incompatible performance measures, varying tolerance of risk as well as differences in hierarchy, governance, work patterns and practices. To highlight the contribution of the patient in coordination between groups, we describe their role during three stages of discharge 1) post-operative ward care, 2) preparation for discharge and 3) post-discharge community care. Each of these points involved different forms of professional-practice coordination, moving from 'tightly knit' coordination

immediately prior to discharge, to looser and more open-ended forms of coordination as the patient moved out into the community. This placed changing requirements for coordination on the patient as they moved through the care pathway.

INSERT TABLE 2 'Professional-practice groups routinely involved in discharge activities' ABOUT HERE

Ward based care: patient as boundary object

Within both hospitals, immediate post-operative care was located in specialist orthopaedic wards, where care pathways were underpinned by the national Hip Fracture Database audit. Audit measurements were regularly cited by staff as structuring their work, and prescribed specific care requirements for each professional group. National audit was overlaid with local contracts that set an 11-day 'target maximum' length of hospital stay, driving staff to progress patients rapidly towards discharge.

> '*if you look through the pathway, [Physiotherapy] are identified early on, i.e. the patient comes in through Accident and Emergency, they are hopefully operated on between twenty four and thirty six hours, ideally twenty four and then the further following day is when we introduce ourselves to the patient, get them up and progress them*.' (Lead Physiotherapist)

Key profession-practice groups involved at this stage were orthopaedic surgeons, who monitored patient recovery from surgery through daily ward rounds; orthogeriatric physicians who specialised in the wider physical health of patients; and ward nurses and therapists who supported on-going patient recovery and early physiotherapy. These groups worked in close proximity, sharing the same ward spaces, nursing desk, equipment rooms, computer terminals and rest areas, and were in regular communication throughout the working day, especially through structured ward-based activities such as the ward round, handover meetings and weekly MDT [multi-disciplinary team] meetings.

> *'Well, we discuss at morning handover and MDT, but we see [OTs and PTs] on the ward each day, we know them. The doctors you bleep them and generally you would see them on the ward daily and you can say can you see such and such'* (Ward Nurse)

As noted in the literature, points of disagreement between professional-practice groups were evident in everyday care, such as the readiness of a patient to commence certain therapies. Overall however, there was a sense of a dominant 'script' with mutual understanding of how roles and responsibilities for ward-based care were distributed and accomplished. Groups were quick to pull each other up on incomplete tasks or comment on the quality of communication processes of other groups.

1   *'We increasingly noticed, and we worked with nursing staff, that the*

2   *morning handovers weren't as good as they could be, so we developed a new*

3   *tool that has to be signed so everyone knows [the nursing shift] is up to*

4   *speed'* (Orthogeriatrician)

5

6   At this stage, the patient played a relatively passive role in inter-professional

7   coordination, representing a prominent common object around which multiple

8   professional-practice groups choreographed their work. This was well

9   illustrated in weekly MDT meetings in which patient care was reviewed and

10   discharge plans developed through scripted inter-professional interactions. For

11   each patient, a professional representative reported progress on their aspect of

12   care, for example weight-bearing status (physiotherapist), bone recovery

13   (surgeon), presence of infection (nurse), or engagement with living tasks

14   (occupational therapist). Although each articulated a different ontology of the

15   patient (Mol, 2002) based on distinct professional knowledge domains, the

16   cumulative reports of each professional group representative could contribute to

17   a shared understanding of the patients' progress along the care pathway.

18

19   **Lead nurse:** *'Next is Mr Jones, bay 2 bed 3, three days post-op, still not up,*

20   *any progress?'*

21   **Physiotherapist** *'I've been this morning, still very little movement, he's*

22   *really weak'*

23   **Orthopaedic doctor** *' It was a complex hemiarthroplasty, there wasn't*

24   *much good bone to go into […]'*

1   ***Occupational therapist*** *'he actually seemed better today, we had a good*

2   *chat but yeah...'*

3   ***Lead nurse:*** *'OK so can we monitor and full report back on Thursday?' Next*

4   *is Mrs Ahmed [...]'*

5

6 Significantly, the physical presence of the patient in the ward bed provided a

7 point of orientation. In both hospitals, for example, patient progress was

8 recorded on interactive 'smart' boards, but there were only used intermittently.

9 Instead, clinicians observed (often at a distance) patients occupying ward beds

10 as a more immediate visual indicator of care progress, workload and resources

11 availability, with clinicians often pointing at their patients from behind the

12 nurses' desk when discussing on-going tasks.

13

14 In descriptions of their hospital stay, patients often discussed themselves as

15 willing to accept their position as compliant recipients of care akin to Parson's

16 (1951) sick role. Although overall judgment of hospital care varied dramatically

17 across participants, they typically described themselves as seeking to cooperate

18 with the 'good' or 'bad' care provided by health professionals, rather than

19 actively coordinating their care.

20

21 *'It's hard when this time arrives, you know, when you're getting poorly [...] I*

22 *have nothing really to complain. People are very kind. Very kind. The nurses*

23 *as well have got good patience.'* (Female patient)

24

1   *'I'm determined to get better and if these people [hospital staff] want to put*

2   *some effort into it, I will go along with them. I can't say more than that can I?'*

3   (Male patient)

4

5   **Preparing for discharge: patient as contested boundary subject**

6   Following initial stages of post-operative care and early rehabilitation, ward staff

7   began preparing for discharge. Patients assessed as 'good' or 'well', i.e.

8   responding positively to treatment, were discharged three to four days following

9   surgery. Those assessed as 'difficult' or 'poorly' were assessed as requiring more

10   attention to their physical and psychosocial well-being, resulting in a long and

11   more complicated route to discharge. Specifically, the discharge of more

12   complicated patients involved daily challenges for staff that ranged from

13   ensuring the physical suitability or 'readiness' to leave the hospital, as well as

14   arranging the appropriate levels of on-going care in community settings.

15   Arranging on-going care was often made difficult by the lack of resources in the

16   community (e.g. rehabilitation beds, home equipment supplies, care workers),

17   and difficulties in coordinating with external agencies (e.g. communication

18   breakdowns, misaligned working patterns).

19

20   *'In theory we should be able to move everyone out within 10 days regardless*

21   *[...] I said in theory, but there are a million things that go wrong'*

22   (Physiotherapist)

23

24   Once the patient was assessed as recovered from surgery, the primary

25   responsibility for their care was transferred from surgeons to ward-based

medics, nurses and therapists. These clinicians seemed determined to maintain a strong 'production' focus including throughput of patients.

> '*Our role is as an acute hip fracture service. Immediate recovery, not long-term rehabilitation.*' (Discharge Liaison Nurse)

> '*if the patient refuses to go, so you can be still stuck in, the patient is in day seven and they have agreed to get a bed, day eight, so the wrong hospital. So they get stuck. We should be able to kick them out*' (Physiotherapist)

In comparison with the immediate stages of post-operative care, the division of responsibilities for discharge planning was more ambiguous, exacerbated by inter-group tensions over the appropriate level of patient involvement in assessments and care planning. Depending on the intended discharge destination, staff involved in discharge planning needed to navigate a multi-faceted boundary infrastructure, including overlapping and repetitious paper-based forms, legal standards, communication channels and information technologies. For example, referrals from the acute hospital to social services involved completing physical and mental health assessments, followed by a two-stage notification process and a funding decision tool.

> '*The Continuing Healthcare Checklist [CHC] is filled out, which is a checklist to see whether this patient will be [funded by] health or social, and then you fill out section two, which is an entire form to say the patient will require social services. [...] And then they will send that off as section five and the*

social services have to respond within twenty-four or forty eight hours.'
(Physiotherapy Lead)

Responsibility for completing bureaucratic tasks was often discussed, with accusations of 'buck passing' either between shifts or between professional-practice groups.

'There's pressure on us because at the MDT, if it's suggested, like last Tuesday, 'Right. These three patients need CHC, Section Twos have been identified. They need a package of care. We're now on their eight day of the pathway.' We then go to the meeting today and that CHC hasn't been done. "Why hasn't it been done?' (Ward Nurse)

'So it's always when you've got the [bed availability] piece of paper, it's always the last person to sign it is the rotten egg' (Occupational Therapist)

For busy (and more junior) ward nurses, engaging patients in technical assessments was a daunting and time-consuming task, for which they often had not received training. It was often seen as more straightforward to collect the required information through desk-based 'detective work'. It was surprising to observe, for example, how nurses often used patients' residential postcodes to access 'street view' on Google Earth to answer questions on patients' homes, such as access arrangements. Other assessment forms were required by legislation to be completed alongside patients and carers, including cognitive and

health funding assessments. Junior nurses, and those less familiar with the referral system, often found 'active' patient engagement difficult to realise.

'the big thing from discharge paperwork that is a bit of a nightmare like I say is the CHC. We have to do it with either the patient or a family member. Some of the nursing staff are nervous about doing that because it's talking about the patient's cognitive ability, behavioural issues and actually facing them outwards with the relatives - they feel quite intimated' (Lead Nurse)

In contrast, occupation therapists and orthogeriatric doctors appeared more enthusiastic about interacting with patients and families to develop personalised care plans. These groups were often observed during handovers and MDT meetings advocating for family meetings to discuss care plans with patients and families. This was criticised by other clinical groups as 'holding up' discharge and disrupting patient throughput.

'we have the background, we have to learn about mental health within our training so we tend to be quite holistic. We tend to look at those things that other people don't necessarily see' (Occupational Therapist)

'you think the patient is nearly ready, as good as they will get, and then [OTs] get involved and suddenly there are hundreds more things that we need to sort out' (Physiotherapist)

From the accounts of professionals, as well as patients and family, patients' engagement with the discharge planning process varied markedly, not least due to varying cognitive function. Patients and families did not necessarily recognise the benefits of participating in the assessment processes, and often described participation as bureaucratic and repetitive.

'Well they went through it all with us. Took a bloody age actually, we had to go through all of these forms and tell them what we thought about this and that. That one [Nurse] was nice though' (Female patient)

'A lot of the patients cannot understand why you're actually there and why you need to do these assessments with them.' (Occupational Therapist)

What appeared important to patients was not necessarily the degree to which they participated in care planning, which could equally be described as a burden, but whether they felt they had received appropriate and well-coordinated care.

'From half-past five in the morning to strip my bed and I was sitting on a chair from that time till I got home. It had gone eight o'clock at night. I felt like I wanted to cry because, you know, I felt they just didn't care.' (Female patient)

Post discharge: patient as reluctant boundary spanner

Following hospital discharge, care journeys became exponentially more diverse as patients dispersed to multiple settings dependent on their wellbeing and personal circumstances, i.e. home, care home, rehabilitation centre, or community hospital. Approximately one third of patients went on to

rehabilitation facilities, a fifth went to nursing or residential homes and the remainder returned to their own home, sometimes with extensive packages of care from social services and community nursing teams. Post-discharge care involved a large number of external agencies, including Social Services, General Practitioners, community and mental health services, nursing and residential homes and equipment suppliers.

In contrast to the hospital setting, interactions between community-based professional-practice groups were much less frequent, with limited opportunities for face-to-face interaction and reliance on indirect communication around separate patient-encounters. Correspondingly, patients and families played a more active coordinating role, acting as intermediaries between professional-practice groups to reconcile differences in working practices and perceived failures of communication. To illustrate, social services across both study regions had recently undergone efficiency-led re-organisation involving the installation of a central 'contact centre' to allocate referrals amongst local social work teams, replacing former arrangements for hospital-based social workers. Re-organisation was seen as causing significant failures of communication.

> '*We haven't got social workers in the hospital. [this happened] In the last three weeks, four weeks. They refuse to come out and see the patient. We then have like six different phone calls in an hour from different social workers about patients. So you spend that hour on the phone to different*

1   *social workers and you're answering the same question that you've just*

2   *answered'* (Occupational Therapist)

3

4   Social workers described how the re-organisations meant they had limited

5   knowledge of the patients being discharged beyond generic referral information,

6   making it difficult to assess and plan for post-discharge care. Social workers

7   commonly complained they now lacked direct contact with expert hospital

8   clinicians, often relying on a simple written description of the care provided (on

9   the referral form) without the ability to ask questions about patients'

10   rehabilitation needs.

11

12   *'The disconnect now is pretty massive – [social workers] often have very*

13   *little idea of what is needed when we get to that first appointment. That's*

14   *when we know where to go'* (Social Services Manager)

15

16   *'All I want to know is that the risk is being appropriately managed and if he*

17   *goes home and knocks his thing off his face and dies in his sleep, that we've*

18   *done everything we can to do our best to prevent that from happening. And*

19   *I need a medic to tell me that because I don't know*.' (Social worker)

20

21   Levels of trust between health and social care providers were evidently low, and

22   there was widespread scepticism about the usefulness of information contained

23   within documents that were shared across dispersed groups.

24

1 '*the discharge summary that goes out, patients get a copy of that, but often*

2 *because it's filled in by the junior doctors it's quite a cursory document at*

3 *times and it doesn't necessarily reflect what's happened.'*

4 (Orthogeriatrician)

5

6 '*I sometimes get these letters* [holding an example]; *often they're next to*

7 *useless. I just have to start again and ask the patient if and when they show*

8 *up'* (General Practitioner)

9

10 Despite multiple referral systems and channels of communication, the

11 coordination of services in the community appeared to rely on patients and

12 families acting as a 'backup' point of coordination. Rather than through planned

13 'involvement' purposefully instigated by professional groups, patients were seen

14 to become increasingly involved in navigating the system when gaps appeared to

15 them.

16 '*Well we should get referrals through the SPOC [single point of contact] and*

17 *then receive these [referral forms] complete. But quite a few times recently*

18 *we just get calls "where are you" kind of thing [from the patients]*' (Social

19 worker)

20

21 Outside of hospital, patients and family members understood themselves as

22 needing to be more pro-active in coordinating the work of various groups, and

23 described learning from their experiences of the gaps in inter-agency care. For

24 example, patients and family members described the steps they had taken to

organise referrals and follow-up care, shared information between groups and chased incomplete or missing care tasks.

'I just got [husband] to phone [re-ablement team] and we said you should have been here before 10. We've supposed to have the [community] nurse coming out any time to take out the stitches and I'm getting more and nervous that they won't come and we'll have to chase them' (Female patient)

'I'm having these injections for the DVT thing and they said I could have a nurse come in for that, but I just do it myself.' (Male patient)

'when I took her in, to the physician's assistant and I even know his name because I saw his badge. And I said to him, because he said about blood pressure or something. I said, 'No, but she's on digoxin for irregular heartbeat'. (Nursing home carer of female patient)

Over time, patients and carers appeared to gain an increasing knowledge of the health and social care system, and discussed taking on increasing responsibility for orchestrating care, through use of 'professional' language of technology, treatments, roles and responsibilities.

Discussion

The findings show how the coordinating role of patients changed as they move through the stages of discharge, from the acute hospital and into community

setting. In early post-surgery recovery, a common script amongst ward-based clinical groups helped coordinate the tasks of rehabilitation and care, seemingly underpinned by a shared understanding of the relatively passive and static post-operative patient. Frequent face-to-face interactions within the shared physical space of the hospital ward, together with the boundary infrastructure of the post-surgical pathway combined to support the development of a common object of care, but left little room for patient involvement in decision making. Parsons (1975) made clear that his 'sick role' concept did not necessarily (or mostly) imply that patients become passive objects for professional manipulation, but rather that particular features of context, including the nature of the condition and care setting, may lead patients to play a more or less passive or active role while cooperating with health professionals to aid their recovery. Here, inter-professional work was coordinated through reference to patients (their bodies and health status) *as if* they adhere passively and statically to existing professional categories, with the post-operative patient conforming sufficiently to this to allow coordination to continue. In this respect, the post-operative patient might be regarded as a 'de-activated' boundary object at the centre of a highly prescribed and tightly managed care pathway

As preparations for hospital discharge progressed, the coordination of professional input became less prescribed, as the individual circumstances affecting longer-term patient recovery were considered in care planning. Care trajectories diversified in preparing for discharge and the central challenge of coordination concerned divisions between the clinical and the psychosocial aspects of care, resulting in greater tension over the appropriate role of the

1   patient. In this context, the patient took on a more ambiguous and contested

2   coordinating role. Certain aspects of the discharge process required patients to

3   more actively contribute their subjective preferences, experiences and intentions

4   to the formation of care plans. During preparation for discharge, we then see the

5   patient as 'activated' boundary subject, defined by a rising (although still

6   contested) expectation amongst the actors involved that patients' subjectivities

7   will contribute to coordination. This co-existed alongside - and within - the

8   standardised bureaucratic processes, seen as essential to maintain the

9   throughput of the hospital department, which required a continuing level of

10   objectification.   As such, the patient existed in a dual-state of being

11   simultaneously an object of managed inter-professional coordination, and also a

12   subject of individualised care planning.   This duality created tensions for

13   discharge planning, as demands for streamlined care management were often

14   complicated by personal circumstances and, at the same time, the scope for

15   clinicians to address individualised care needs was limited by the need to

16   manage care to prescribed pathways and time-scales.

17

18   Following discharge from hospital, interaction between professional groups

19   became much looser and more dispersed, with gaps in coordination and explicit

20   conflict and disagreement. As noted elsewhere (Levina and Vaast,, 2005), remote

21   communication tools were often insufficient to achieve the level of mutual

22   understanding required for cross-disciplinary working, and coordination

23   between dispersed agencies delivering community-based care was seen as

24   threatening patient safety (Waring et al., 2015). While patients remained a

25   fulcrum around which individual groups organised their services, away from the

1 mutual gaze of the MDT they no longer provided a reliable and shared boundary

2 object. In this context, patients and carers found themselves more autonomously

3 responsibly for navigating elements of the health and social care system, and felt

4 required to actively instigate care activities in light of perceived failings of inter-

5 organisational coordination. In view of this, patients and families could be

6 described as taking up a type of 'boundary spanner' role in which they actively

7 needed to mediate the professional boundaries widely shown to complicate

8 post-discharge care (Glasby 2000). Williams (2002) defines boundary spanners

9 as the key agents or intermediaries that enable effective cross-boundary

10 coordination, involving the use of particular social skills, abilities and personal

11 characteristics. While much literature on boundary spanners assumes high

12 degrees of individual agency, here we see such agency as an extension of the

13 socially conditioned boundary subject, where individual responsible for

14 coordinating care arises from the minimal support from state health and social

15 care agencies. This required patients and families to learn new skills and adopt

16 new practices of coordination, but it also required them to accept themselves as

17 agents of their own care.

18

19 Previous literature has identified the contribution of various boundary objects to

20 the coordination of care across health and social care boundaries (Allen, 2009;

21 Oborn et al, 2013). The shifting boundary role of the patient described here

22 sheds further light on the challenge of professional boundaries, highlighting both

23 the coordinating role played by the objects at the centre of the care process as

24 well as their contested nature. On one hand, when patients act as boundary

25 objects they represent a salient point of common orientation and allowed

1   interpretive flexibility across the professional-practice groups providing care.

2   This contrasted with many of the purposefully designed boundary tools intended

3   to facilitated discharge, which were often limited to particular boundaries and

4   disconnected from work practice. On the other hand, patients did not afford the

5   standardisation expected of other elements of the boundary infrastructure

6   (Timmermans and Areling, 2009), with the heterogeneity of patients remaining a

7   central challenge of organising multi-professional care. Previous literature on

8   boundary objects has avoided casting people as occupying this role. We argue

9   this places artificial limits on the concept, unsupported by the theoretical

10   premises that underpin it, which hold that boundary objects are enacted into

11   being through cross-boundary use (Star 2010), with our research demonstrating

12   the patient can and does routinely act as a boundary object at the centre of the

13   cross boundary coordination under certain conditions. However, while all

14   boundary objects are socially constructed and may be considered to play an

15   active role in the coordination process, patients remain distinct from other

16   boundary objects previously considered due to their potential to move into the

17   role of boundary subject, characterised by a shared expectation that patients

18   subjectivities should contribute to the coordination of their own care.

19

20   In certain respects, this study reflects Mol's (2002; 2008) work in observing the

21   multiplicity of patient bodies, enacted through the technologies and practices of

22   multi-professional care. However, in foregrounding professional boundaries, and

23   including patients' and families' reflections on their care, we highlight the

24   tensions that underpin the multiple formations of patients' as objects *and* as

25   subjects of coordination. New activities to elicit 'choice and voice' offer

opportunity for professional and occupational groups with a remit to account for holistic and individualised care needs in their work; in turn, such activities encourage patients to make decisions and express views in order to become an active contributor to the management of their care. Drawing on Foucault's (1991) work, empowering patients to be actively involved in their own care can be seen as a form of 'neoliberal' or 'entrepreneurial' governmentality in the absence of more directive (or disciplinary) professional care. In this sense, clinical groups take on a pastoral role in re-constituting patients' subjectivities and establishing the moral parameters of involved conduct (McGivern et al. 2017; Waring and Latif 2017), in such ways that patients (as boundary subjects) take responsibility not only for managing their own care, but by implication for coordinating care services in the absence of effective coordinating technologies to mediate professional boundaries.

Our findings provide a rejoinder to existing patient involvement literature (O'Hara and Lawton, 2016; Ellins et al., 2012). We suggest that patients are central to the coordination process, but that this role is heterogeneous, not limited to prescribed decision-making processes and may entail a more active coordinating role in repairing or making up for deficiencies in formal organisation (O'Hara et al 2018). Patient involvement and empowerment are not straightforwardly produced, but rather sit more comfortably with professional-practice groups whose knowledge and expertise rests on accounting for the personal and social circumstances of patients and service users, while other groups may be reluctant to engage or resist these tasks. Our study suggests we cannot take for granted a direct correlation between active involvement in the

care process and increasingly positive experiences of care. Indeed, our study found instances of patients' reporting positive experiences whilst occupying relatively passive roles as boundary objects and conversely, patients reporting negative experiences of being called upon to express subjective wishes or exhibit agency as the coordination of care.

Active coordination and decision making clearly involves additional work, and patients and family members were often surprised at this effort and frustrated by the gaps they saw in inter-professional coordination. In other words, we can consider patients and families as intrinsic to the translational work (Allen, 2014a) of moving themselves across the health and social care system. This perhaps suggests more consideration needs to be placed on preparing patients for their boundary roles. Writing to propose a vision of the future of health services in 1988, Strauss and Corbin argued we should recognise that it is the ill and their families who do the major work of managing chronic illness and therefore a new relationship between acute care and the patient should be installed which takes this into account. This study suggests we are still trying to find a way to address this call.

Conclusion

Patient involvement literature argues that stimulating patients and families involvement in the coordination of health and care systems will lead to improvements in care quality. This study finds patients already making a central contribution to the coordination process, but that the form of this contribution is dependent on wider relations with and between agencies contributing to their

care. Active involvement is not an unequivocal 'good' but plays into the professional politics and gaps in coordination within a health and social care system under significant strain. This does not necessarily suggest ambitions to further patients' involvement should be curtailed, but it does indicate that more could be done to understand the implications of involvement activities at the system level. As healthcare systems experience common challenges of stretched resources and growing demand, the expectations placed on citizens when adopting the role of the patient appears a pressing topic for contemporary debate.

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