

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

4

5 **Abstract**

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

1 their families and carers play an increasingly active role in coordination, often in
2 light of perceived gaps in coordination between care providers. This paper argues
3 that whilst the need for patient and carer involvement is becoming increasingly
4 evident, such involvement plays into, and is mediated through, existing relations
5 between professional and practice groups. Patient and carer involvement is
6 therefore not straightforward and should be considered across the health and care
7 systems in order to meaningfully improve care quality.

8

9 **Keywords**

10 United Kingdom

11 Boundary objects

12 Coordinated care

13 Patient involvement

14 Professional boundaries

15 Professions

16 Complexity

17

18

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24

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 basis
16 for improved cross-boundary coordination (O'Hara and Lawton, 2016; Ellins et al.,
17 2012). Specifically, patients and families are identified as the sole consistent
18 presence across the times, spaces and relationships of complex care systems. This
19 therefore makes them ideally placed to act as the fulcrum around which services
20 are organised, especially for helping to coordinate care across the professional
21 and organisational boundaries that are shown to shape care processes. Drawing
22 on organisational theory, patients and families might be re-cast as 'boundary
23 spanners' (Williams, 2002), given their unique position to manage the interface
24 between different occupations and organisations, especially to support
25 communication and coordination amongst disparate groups. Research shows, for

1 example, patient involvement in care planning and integration can lead to
2 improvements in clinical outcomes and patient experience (Dyrstad et al., 2015;
3 Flink et al., 2012).

4

5 While patients' involvement has a strong normative appeal, a wealth of qualitative
6 and quantitative studies suggest there are enduring limits to patients' ability to
7 adopt a coordinating role (Joseph-Williams et al., 2014). Prioritising patients'
8 subjective experiences stands against dominant biomedical evidence, rooted in
9 objectivity and quantification at the aggregate level; patient views are therefore
10 only partially and problematically incorporated into clinical decision-making
11 (May et al., 2006). Evidence-based medicine - marshalled into healthcare practice
12 through the proliferation of bureaucratic technologies such as clinical guidelines,
13 decision tools, checklists and performance indicators - requires clinical
14 professionals to adopt increasingly standardised practices (Timmermans and
15 Berg, 1997). Standardisation shapes not only the work of individual professionals,
16 but also forms the basis of cross-boundary working, itself dependent on routine
17 and typification. Highlighting this, Allen's work (2014a; 2018) identifies the role
18 of 'translational mobilisation'; the transformation of people into organisationally
19 recognised patients, reconciling their divergent needs with systems, resources
20 and care pathways. Clinical work, Allen argues, is increasingly constituted by the
21 efforts of translating patients across parallel bureaucratic systems within and
22 across organisations. As such, the status of patients as both the agents and objects
23 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 Science
4 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 of
13 the hospital into loosely organised community and domestic settings. In doing so,
14 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 and
19 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 organisational
10 boundaries, creating divisions between communities of practice (Lave and
11 Wenger, 1991). Within organisational research, boundaries between such
12 professional-practice groupings have been considered around three overlapping
13 domains (Ferlie et al., 2005). First, boundaries of knowledge, with professions
14 defining themselves by specific forms of expertise. This is exemplified by the
15 difference between the hierarchy of bio-medical evidence prioritised in acute
16 medicine, against the deliberative and situated understandings valued in social
17 care (Webb, 2001). Second, boundaries of identity and culture, including the
18 extent to which professional groups value inter-professional decision-making or
19 prioritise patient involvement in their own care (Dent and Whitehead, 2013). And
20 third, boundaries of organisation including the established routines, rules,
21 resources, and divisions of labour present in professional organisations
22 (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

1 boundaries between science and non-science, for example, have provided the
2 impetus for research on 'boundary work' (Gieryn 1983), and of particular
3 relevance to this study, the concept of 'boundary objects'. Star and Griesemer
4 (1989) identify boundary objects as 'things' that have divergent meanings and
5 uses for the different social groups, but which maintain sufficient common identity
6 to provide the basis for collaborative endeavour. Star and Griesemer (1989)
7 identified repositories (library catalogues), ideal types (blueprints), objects with
8 coincidental boundaries (maps) and standardised forms as common objects in
9 scientific enquiry that enables specialist to coordinate their distinct activities.

10

11 Qualitative research has elaborated various forms boundary objects can take (Fox,
12 2011; Swan et al., 2007), the processes by which they foster, or limit, collaboration
13 (Oswick and Robertson, 2009) and the relationship between objects, boundaries
14 and social worlds (Bechky, 2003; Swan et al., 2007). For instance, theories (Fox,
15 2011), phrases (Brand and Jax, 2007), and practices (Owens, 2015) have all been
16 interpreted as boundary objects with variable implications for collaboration.
17 Within healthcare, Allen's (2009; 2014b) research examines collaboration
18 between professional, managerial and service user groups in the process of
19 developing new care pathways. This finds participants using considerable
20 political and organisational skill to design pathway tools (boundary objects) that
21 afford space to negotiate tensions between professional groups. Keshet et al.,
22 (2013) demonstrate how multiple boundary objects allow 'loose collaboration'
23 across the social-structural and epistemic boundaries between alternative and
24 conventional medicine, highlighting in particular the importance of epistemic 'fit'
25 between objects and the wider institutional environment.

1

2 There has been less consideration of how people, or human bodies, act as
3 boundary objects. This is perhaps surprising given the analytic equivalence
4 afforded to human and non-human entities within Actor Network Theory and STS.
5 A notable exception is Mol's (2002) examination of how patients' bodies and
6 diseases are enacted heterogeneously in the everyday performance of cross-
7 disciplinary medical work, with different versions of disease rendered knowable
8 through the application of multiple technologies and fields of medical knowledge.
9 Here, the body acts as a boundary object for professional-practice groups, as their
10 distinct forms of practice 'hang together' through their pluralistic enactment of
11 the body, related to their own technologies and practices of work. Although this
12 demonstrates the essential role of the patient as a central object in coordinating
13 healthcare work, Mol's work focuses on the hospital environment, rather than the
14 contribution of the patient to coordination across complex systems of care.

15

16 It is worth recognising that examining the patient as a boundary object could
17 appear contradictory to the aspirations of the patient involvement movement, i.e.
18 holding patients as passive objects of professional practice. However, as
19 Timmermans and Almeling (2009) argue 'objectification' serves a variety of ends
20 for patients as well as for professionals and organisations. Medical advancement
21 depends upon professional specialisation, increasingly fragmenting the body into
22 constituent elements. This, Timmermans and Almeling (2009) argue, can be
23 experienced as alienating, empowering or restorative, depending on whether the
24 patient feels involved in the care process and/or whether treatments are felt to
25 lead to improved experiences of health and wellbeing. As Cussins (1996)

1 illustrates in the context of infertility treatment, patients may in fact demonstrate
2 agency through participating in self-objectification as they actively seek to
3 improve their chance of successful reproductive outcome. Further discussed by
4 Prentice (2003), professional socialisation involves taking on distinct professional
5 cultural rules on acceptable 'object formation' whilst avoiding problematic
6 'objectification'.

7

8 This suggests that rather than a clear division between patients as passive objects
9 of care, or patients as active agents, we should instead look for different forms and
10 implications of objectification, especially at the intersection of different
11 professional boundaries, where varying interests, knowledge and practices are
12 involved in the coordination of care. For example, we can identify a comparatively
13 'narrow' understanding of ailments or body parts fitting with the knowledge of
14 higher status and more specialised medical and surgical groups (Prentice, 2013),
15 and broader or 'holistic' understandings of patients amongst lower status
16 therapists and social care communities (Finlay, 2001). However, the implications
17 of these different care 'objects' on coordination are yet to be considered. This
18 study investigated how professional groups engage in such object formation, to
19 consider the patient's role in coordinating across boundaries in complex care
20 processes.

21

22

23 **Coordinating Hospital discharge**

24 The challenges of coordinating care across professional boundaries is exemplified
25 by hospital discharge; the transfer of care from the hospital to a community setting

1 (Aase et al., 2017; Glasby et al., 2008). The transfer of patients between care
2 settings is widely recognised as a vulnerable and high-risk stage in the patient
3 journey (Forster et al. 2003; Moore, et al., 2003; Kripalani et al., 2007a).
4 Prominent threats to safety including problems with medicine reconciliation,
5 managing wounds and infections, and continuity of care (Burke, 2003; Grimes et
6 al., 2008; Kripalani et al., 2007b; Waring et al. 2013). The threats to safe hospital
7 discharge are often rooted in the complexities of coordinating care across
8 professional boundaries. As patients move out of hospital, care responsibilities
9 pass between professional groupings (e.g. hospital clinicians and community
10 social workers), between organisations, (e.g. acute and community hospitals),
11 between care sectors (e.g. health and social care), and between economic sectors,
12 (e.g. from the public to not-for-profit or private sector). Ethnographic research on
13 discharge pathways reveals significant contradictions and limitations in the social
14 organisation of care (Wells, 1997), including conflict between the needs of
15 individual patients and the multiple bureaucratic systems through which their
16 care is organised. Hospital discharge is therefore a critical case to examine the
17 patients' role in coordination across professional boundaries within complex
18 systems of care.

19

20 **Methodology**

21 This paper draws upon the findings of a two-year ethnographic study of the social
22 organisation of hospital discharge. Taking an ethnographic approach allowed for
23 direct observation and 'thick' description of the locally important elements of
24 discharge planning and care transitions, which were interpreted in terms of the
25 social and cultural boundaries that shaped the social organisation of hospital

1 discharge. All relevant ethical approvals were obtained through the UK NREC
2 prior to research commencing.

3

4 The ethnographic study was undertaken in two regional care systems in the
5 English National Health Service (NHS). Each system was organised around a
6 medium-sized English city with a single NHS Trust providing acute care; in excess
7 of 20 NHS primary care providers (General Practitioners); and between two and
8 four community NHS hospitals and rehabilitation services. Each system also
9 involved social care commissioners and providers, in the form of local authority
10 (municipal) 'social services', and a large range of public, private and third sector
11 social care providers.

12

13 Within each of these care systems, the study focused on the discharge of patients
14 receiving inpatient hip replacement surgery and physiotherapy, followed by
15 community-based on-going physiotherapy and other rehabilitation care. Hip
16 fracture was chosen as a condition predominantly affecting frail older people who
17 often have multiple co-morbidities including both physical and cognitive
18 impairment (Giusti, et al., 2011). As such, discharge planning is often complex,
19 involving consideration of past and future long-term health and social care needs.
20 Care for hip fracture patients requires a wide range of acute and community
21 specialists to work in close cooperation (Tierney and Vallis, 1999), including
22 orthopaedic and orthogeriatric medical teams, nursing groups, therapists and
23 social care providers. Readmission rates are relatively high, and previous studies
24 have shown the period following hip fracture present challenges for organising
25 safe and effective ongoing care (O'Cathain, 1994). Finally, hip fracture services in

1 the UK have been subject to national policies to standardise care pathways,
2 including guidelines for multi-disciplinary care and are therefore an appropriate
3 site to investigate coordination across professional-practice groups.

4

5 Data were collected (2011-2013) through qualitative interviews and non-
6 participation observations of discharge planning and care transitions over a two
7 year period. Approximately 120 hours of observations were undertaken over a
8 two year period, focusing on the temporal and spatial organisation of daily work
9 (schedule of ward rounds, meetings, handovers, discharge times); identifying key
10 events and activities (MDTs, drug rounds); identifying key individuals or groups
11 ascribed with knowledge sharing roles (discharge co-ordinators, clinical leads). In
12 addition, semi-structured interviews were carried out with staff (69 staff
13 interviewees across the hip fracture pathway, see table 1). Interviews with staff
14 lasted on average 45 minutes and explored participants' role, the routines and
15 experiences of coordinating with other staff groups, the processes of hospital
16 discharge and perceived risks and challenges. The study also 'followed' the
17 discharge journeys of 17 patients, including interviews at up to three time points
18 (once in hospital and two times up to six week after discharge).

19

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

21

22 Interpretative qualitative data analysis was undertaken to develop descriptive
23 and contextualised understanding of cross-boundary work and its contribution to
24 discharge. This involved an iterative process of close reading of data, coding,
25 constant comparison, elaboration of emerging themes and re-engaging with wider

1 literature. Themes were developed through first independent open coding by both
2 members of the research team on samples of the data, with initial codes used to
3 code the rest of the data, with additional codes added and refined at regular
4 intervals during the analysis process. As the coding process progressed, thematic
5 categories were identified. While the study was oriented to investigate issues of
6 coordination across boundaries, the current focus on the patients' boundary role
7 emerged only through data collection and analysis, becoming evident in light of
8 limitations of other mechanisms of coordination.

9

10 **Findings**

11 In both study sites, the work of managing discharge was dispersed across multiple
12 professional and occupational groups (**see Table 2**). Differences in the
13 knowledge, culture and organisation of these professional-practice groups made
14 discharging patients a continual challenge. Commonly discussed boundary
15 challenges included discordant IT systems, incompatible performance measures,
16 varying tolerance of risk as well as differences in hierarchy, governance, work
17 patterns and practices. To highlight the contribution of the patient in coordination
18 between groups, we describe their role during three stages of discharge 1) post-
19 operative ward care, 2) preparation for discharge and 3) post-discharge
20 community care. Each of these points involved different forms of professional-
21 practice coordination, moving from 'tightly knit' coordination immediately prior
22 to discharge, to looser and more open-ended forms of coordination as the patient
23 moved out into the community. This placed changing requirements for
24 coordination on the patient as they moved through the care pathway.

25

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

3
4 **Ward based care: patient as boundary object**

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

12
13 *'if you look through the pathway, [Physiotherapy] are identified early on, i.e.*
14 *the patient comes in through Accident and Emergency, they are hopefully*
15 *operated on between twenty four and thirty six hours, ideally twenty four and*
16 *then the further following day is when we introduce ourselves to the patient,*
17 *get them up and progress them.'* (Lead Physiotherapist)

18
19 Key profession-practice groups involved at this stage were orthopaedic surgeons,
20 who monitored patient recovery from surgery through daily ward rounds;
21 orthogeriatric physicians who specialised in the wider physical health of patients;
22 and ward nurses and therapists who supported on-going patient recovery and
23 early physiotherapy. These groups worked in close proximity, sharing the same
24 ward spaces, nursing desk, equipment rooms, computer terminals and rest areas,

1 and were in regular communication throughout the working day, especially
2 through structured ward-based activities such as the ward round, handover
3 meetings and weekly MDT [multi-disciplinary team] meetings.

4

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

9

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

17

18 *'We increasingly noticed, and we worked with nursing staff, that the morning*
19 *handovers weren't as good as they could be, so we developed a new tool that*
20 *has to be signed so everyone knows [the nursing shift] is up to speed'*
21 (Orthogeriatrician)

22

23 At this stage, the patient played a relatively passive role in inter-professional
24 coordination, representing a prominent common object around which multiple
25 professional-practice groups choreographed their work. This was well illustrated

1 in weekly MDT meetings in which patient care was reviewed and discharge plans
2 developed through scripted inter-professional interactions. For each patient, a
3 professional representative reported progress on their aspect of care, for example
4 weight-bearing status (physiotherapist), bone recovery (surgeon), presence of
5 infection (nurse), or engagement with living tasks (occupational therapist).
6 Although each articulated a different ontology of the patient (Mol, 2002) based on
7 distinct professional knowledge domains, the cumulative reports of each
8 professional group representative could contribute to a shared understanding of
9 the patients' progress along the care pathway.

10

11 ***Lead nurse:** 'Next is Mr Jones, bay 2 bed 3, three days post-op, still not up,*
12 *any progress?'*

13 ***Physiotherapist** 'I've been this morning, still very little movement, he's really*
14 *weak'*

15 ***Orthopaedic doctor** 'It was a complex hemiarthroplasty, there wasn't much*
16 *good bone to go into [...]'*

17 ***Occupational therapist** 'he actually seemed better today, we had a good*
18 *chat but yeah...'*

19 ***Lead nurse:** 'OK so can we monitor and full report back on Thursday?' Next*
20 *is Mrs Ahmed [...]'*

21

22 Significantly, the physical presence of the patient in the ward bed provided a point
23 of orientation. In both hospitals, for example, patient progress was recorded on
24 interactive 'smart' boards, but there were only used intermittently. Instead,
25 clinicians observed (often at a distance) patients occupying ward beds as a more

1 immediate visual indicator of care progress, workload and resources availability,
2 with clinicians often pointing at their patients from behind the nurses' desk when
3 discussing on-going tasks.

4

5 In descriptions of their hospital stay, patients often discussed themselves as
6 willing to accept their position as compliant recipients of care akin to Parson's
7 (1951) sick role. Although overall judgment of hospital care varied dramatically
8 across participants, they typically described themselves as seeking to cooperate
9 with the 'good' or 'bad' care provided by health professionals, rather than actively
10 coordinating their care.

11

12 *'It's hard when this time arrives, you know, when you're getting poorly [...] I have*
13 *nothing really to complain. People are very kind. Very kind. The nurses as well*
14 *have got good patience.'* (Female patient)

15

16 *'I'm determined to get better and if these people [hospital staff] want to put some*
17 *effort into it, I will go along with them. I can't say more than that can I?'* (Male
18 patient)

19

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

21 Following initial stages of post-operative care and early rehabilitation, ward staff
22 began preparing for discharge. Patients assessed as 'good' or 'well', i.e. responding
23 positively to treatment, were discharged three to four days following surgery.
24 Those assessed as 'difficult' or 'poorly' were assessed as requiring more attention
25 to their physical and psychosocial well-being, resulting in a long and more

1 complicated route to discharge. Specifically, the discharge of more complicated
2 patients involved daily challenges for staff that ranged from ensuring the physical
3 suitability or 'readiness' to leave the hospital, as well as arranging the appropriate
4 levels of on-going care in community settings. Arranging on-going care was often
5 made difficult by the lack of resources in the community (e.g. rehabilitation beds,
6 home equipment supplies, care workers), and difficulties in coordinating with
7 external agencies (e.g. communication breakdowns, misaligned working
8 patterns).

9

10 *'In theory we should be able to move everyone out within 10 days regardless*
11 *[...] I said in theory, but there are a million things that go wrong'*
12 (Physiotherapist)

13

14 Once the patient was assessed as recovered from surgery, the primary
15 responsibility for their care was transferred from surgeons to ward-based medics,
16 nurses and therapists. These clinicians seemed determined to maintain a strong
17 'production' focus including throughput of patients.

18

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

21

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

25

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

11

12 *'The Continuing Healthcare Checklist [CHC] is filled out, which is a checklist*
13 *to see whether this patient will be [funded by] health or social, and then you*
14 *fill out section two, which is an entire form to say the patient will require*
15 *social services. [...] And then they will send that off as section five and the*
16 *social services have to respond within twenty-four or forty eight hours.'*

17 (Physiotherapy Lead)

18

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

22

23 *'There's pressure on us because at the MDT, if it's suggested, like last Tuesday,*
24 *'Right. These three patients need CHC, Section Twos have been identified.*
25 *They need a package of care. We're now on their eight day of the pathway.'*

1 *We then go to the meeting today and that CHC hasn't been done. "Why hasn't*
2 *it been done?"* (Ward Nurse)

3

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

6

7 For busy (and more junior) ward nurses, engaging patients in technical
8 assessments was a daunting and time-consuming task, for which they often had
9 not received training. It was often seen as more straightforward to collect the
10 required information through desk-based 'detective work'. It was surprising to
11 observe, for example, how nurses often used patients' residential postcodes to
12 access 'street view' on Google Earth to answer questions on patients' homes, such
13 as access arrangements. Other assessment forms were required by legislation to
14 be completed alongside patients and carers, including cognitive and health
15 funding assessments. Junior nurses, and those less familiar with the referral
16 system, often found 'active' patient engagement difficult to realise.

17

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

23

24 In contrast, occupation therapists and orthogeriatric doctors appeared more
25 enthusiastic about interacting with patients and families to develop personalised

1 care plans. These groups were often observed during handovers and MDT
2 meetings advocating for family meetings to discuss care plans with patients and
3 families. This was criticised by other clinical groups as 'holding up' discharge and
4 disrupting patient throughput.

5

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

9

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

13

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

19

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

23

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

1

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

5

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

9 **Post discharge: patient as reluctant boundary spanner**

10 Following hospital discharge, care journeys became exponentially more diverse
11 as patients dispersed to multiple settings dependent on their wellbeing and
12 personal circumstances, i.e. home, care home, rehabilitation centre, or community
13 hospital. Approximately one third of patients went on to rehabilitation facilities, a
14 fifth went to nursing or residential homes and the remainder returned to their
15 own home, sometimes with extensive packages of care from social services and
16 community nursing teams. Post-discharge care involved a large number of
17 external agencies, including Social Services, General Practitioners, community and
18 mental health services, nursing and residential homes and equipment suppliers.

19

20 In contrast to the hospital setting, interactions between community-based
21 professional-practice groups were much less frequent, with limited opportunities
22 for face-to-face interaction and reliance on indirect communication around
23 separate patient-encounters. Correspondingly, patients and families played a
24 more active coordinating role, acting as intermediaries between professional-
25 practice groups to reconcile differences in working practices and perceived

1 failures of communication. To illustrate, social services across both study regions
2 had recently undergone efficiency-led re-organisation involving the installation of
3 a central 'contact centre' to allocate referrals amongst local social work teams,
4 replacing former arrangements for hospital-based social workers. Re-
5 organisation was seen as causing significant failures of communication.

6

7 *'We haven't got social workers in the hospital. [this happened] In the last*
8 *three weeks, four weeks. They refuse to come out and see the patient. We*
9 *then have like six different phone calls in an hour from different social*
10 *workers about patients. So you spend that hour on the phone to different*
11 *social workers and you're answering the same question that you've just*
12 *answered'* (Occupational Therapist)

13

14 Social workers described how the re-organisations meant they had limited
15 knowledge of the patients being discharged beyond generic referral information,
16 making it difficult to assess and plan for post-discharge care. Social workers
17 commonly complained they now lacked direct contact with expert hospital
18 clinicians, often relying on a simple written description of the care provided (on
19 the referral form) without the ability to ask questions about patients'
20 rehabilitation needs.

21

22 *'The disconnect now is pretty massive – [social workers] often have very little*
23 *idea of what is needed when we get to that first appointment. That's when we*
24 *know where to go'* (Social Services Manager)

25

1 *'All I want to know is that the risk is being appropriately managed and if he*
2 *goes home and knocks his thing off his face and dies in his sleep, that we've*
3 *done everything we can to do our best to prevent that from happening. And*
4 *I need a medic to tell me that because I don't know.'* (Social worker)

5

6 Levels of trust between health and social care providers were evidently low, and
7 there was widespread scepticism about the usefulness of information contained
8 within documents that were shared across dispersed groups.

9

10 *'the discharge summary that goes out, patients get a copy of that, but often*
11 *because it's filled in by the junior doctors it's quite a cursory document at*
12 *times and it doesn't necessarily reflect what's happened.'* (Orthogeriatrician)

13

14 *'I sometimes get these letters [holding an example]; often they're next to*
15 *useless. I just have to start again and ask the patient if and when they show*
16 *up'* (General Practitioner)

17

18 Despite multiple referral systems and channels of communication, the
19 coordination of services in the community appeared to rely on patients and
20 families acting as a 'backup' point of coordination. Rather than through planned
21 'involvement' purposefully instigated by professional groups, patients were seen
22 to become increasingly involved in navigating the system when gaps appeared to
23 them.

24 *'Well we should get referrals through the SPOC [single point of contact] and*
25 *then receive these [referral forms] complete. But quite a few times recently*

1 *we just get calls “where are you” kind of thing [from the patients]’* (Social
2 worker)

3

4 Outside of hospital, patients and family members understood themselves as
5 needing to be more pro-active in coordinating the work of various groups, and
6 described learning from their experiences of the gaps in inter-agency care. For
7 example, patients and family members described the steps they had taken to
8 organise referrals and follow-up care, shared information between groups and
9 chased incomplete or missing care tasks.

10

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

15

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

18

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

23

24 Over time, patients and carers appeared to gain an increasing knowledge of the
25 health and social care system, and discussed taking on increasing responsibility

1 for orchestrating care, through use of 'professional' language of technology,
2 treatments, roles and responsibilities.

3

4 **Discussion**

5 The findings show how the coordinating role of patients changed as they move
6 through the stages of discharge, from the acute hospital and into community
7 setting. In early post-surgery recovery, a common script amongst ward-based
8 clinical groups helped coordinate the tasks of rehabilitation and care, seemingly
9 underpinned by a shared understanding of the relatively passive and static post-
10 operative patient. Frequent face-to-face interactions within the shared physical
11 space of the hospital ward, together with the boundary infrastructure of the post-
12 surgical pathway combined to support the development of a common object of
13 care, but left little room for patient involvement in decision making. Parsons
14 (1975) made clear that his 'sick role' concept did not necessarily (or mostly) imply
15 that patients become passive objects for professional manipulation, but rather
16 that particular features of context, including the nature of the condition and care
17 setting, may lead patients to play a more or less passive or active role while
18 cooperating with health professionals to aid their recovery. Here, inter-
19 professional work was coordinated through reference to patients (their bodies
20 and health status) *as if* they adhere passively and statically to existing professional
21 categories, with the post-operative patient conforming sufficiently to this to allow
22 coordination to continue. In this respect, the post-operative patient might be
23 regarded as a 'de-activated' boundary object at the centre of a highly prescribed
24 and tightly managed care pathway

25

1 As preparations for hospital discharge progressed, the coordination of
2 professional input became less prescribed, as the individual circumstances
3 affecting longer-term patient recovery were considered in care planning. Care
4 trajectories diversified in preparing for discharge and the central challenge of
5 coordination concerned divisions between the clinical and the psychosocial
6 aspects of care, resulting in greater tension over the appropriate role of the
7 patient. In this context, the patient took on a more ambiguous and contested
8 coordinating role. Certain aspects of the discharge process required patients to
9 more actively contribute their subjective preferences, experiences and intentions
10 to the formation of care plans. During preparation for discharge, we then see the
11 patient as 'activated' boundary subject, defined by a rising (although still
12 contested) expectation amongst the actors involved that patients' subjectivities
13 will contribute to coordination. This co-existed alongside - and within - the
14 standardised bureaucratic processes, seen as essential to maintain the throughput
15 of the hospital department, which required a continuing level of objectification.
16 As such, the patient existed in a dual-state of being simultaneously an object of
17 managed inter-professional coordination, and also a subject of individualised care
18 planning. This duality created tensions for discharge planning, as demands for
19 streamlined care management were often complicated by personal circumstances
20 and, at the same time, the scope for clinicians to address individualised care needs
21 was limited by the need to manage care to prescribed pathways and time-scales.

22

23 Following discharge from hospital, interaction between professional groups
24 became much looser and more dispersed, with gaps in coordination and explicit
25 conflict and disagreement. As noted elsewhere (Levina and Vaast,, 2005), remote

1 communication tools were often insufficient to achieve the level of mutual
2 understanding required for cross-disciplinary working, and coordination
3 between dispersed agencies delivering community-based care was seen as
4 threatening patient safety (Waring et al., 2015). While patients remained a
5 fulcrum around which individual groups organised their services, away from the
6 mutual gaze of the MDT they no longer provided a reliable and shared boundary
7 object. In this context, patients and carers found themselves more autonomously
8 responsibly for navigating elements of the health and social care system, and felt
9 required to actively instigate care activities in light of perceived failings of inter-
10 organisational coordination. In view of this, patients and families could be
11 described as taking up a type of 'boundary spanner' role in which they actively
12 needed to mediate the professional boundaries widely shown to complicate post-
13 discharge care (Glasby 2000). Williams (2002) defines boundary spanners as the
14 key agents or intermediaries that enable effective cross-boundary coordination,
15 involving the use of particular social skills, abilities and personal characteristics.
16 While much literature on boundary spanners assumes high degrees of individual
17 agency, here we see such agency as an extension of the socially conditioned
18 boundary subject, where individual responsible for coordinating care arises from
19 the minimal support from state health and social care agencies. This required
20 patients and families to learn new skills and adopt new practices of coordination,
21 but it also required them to accept themselves as agents of their own care.

22

23 Previous literature has identified the contribution of various boundary objects to
24 the coordination of care across health and social care boundaries (Allen, 2009;
25 Oborn et al, 2013). The shifting boundary role of the patient described here sheds

1 further light on the challenge of professional boundaries, highlighting both the
2 coordinating role played by the objects at the centre of the care process as well as
3 their contested nature. On one hand, when patients act as boundary objects they
4 represent a salient point of common orientation and allowed interpretive
5 flexibility across the professional-practice groups providing care. This contrasted
6 with many of the purposefully designed boundary tools intended to facilitated
7 discharge, which were often limited to particular boundaries and disconnected
8 from work practice. On the other hand, patients did not afford the standardisation
9 expected of other elements of the boundary infrastructure (Timmermans and
10 Areling, 2009), with the heterogeneity of patients remaining a central challenge of
11 organising multi-professional care. Previous literature on boundary objects has
12 avoided casting people as occupying this role. We argue this places artificial limits
13 on the concept, unsupported by the theoretical premises that underpin it, which
14 hold that boundary objects are enacted into being through cross-boundary use
15 (Star 2010), with our research demonstrating the patient can and does routinely
16 act as a boundary object at the centre of the cross boundary coordination under
17 certain conditions. However, while all boundary objects are socially constructed
18 and may be considered to play an active role in the coordination process, patients
19 remain distinct from other boundary objects previously considered due to their
20 potential to move into the role of boundary subject, characterised by a shared
21 expectation that patients subjectivities should contribute to the coordination of
22 their own care.

23

24 In certain respects, this study reflects Mol's (2002; 2008) work in observing the
25 multiplicity of patient bodies, enacted through the technologies and practices of

1 multi-professional care. However, in foregrounding professional boundaries, and
2 including patients' and families' reflections on their care, we highlight the tensions
3 that underpin the multiple formations of patients' as objects *and* as subjects of
4 coordination. New activities to elicit 'choice and voice' offer opportunity for
5 professional and occupational groups with a remit to account for holistic and
6 individualised care needs in their work; in turn, such activities encourage patients
7 to make decisions and express views in order to become an active contributor to
8 the management of their care. Drawing on Foucault's (1991) work, empowering
9 patients to be actively involved in their own care can be seen as a form of
10 'neoliberal' or 'entrepreneurial' governmentality in the absence of more directive
11 (or disciplinary) professional care. In this sense, clinical groups take on a pastoral
12 role in re-constituting patients' subjectivities and establishing the moral
13 parameters of involved conduct (McGivern et al. 2017; Waring and Latif 2017), in
14 such ways that patients (as boundary subjects) take responsibility not only for
15 managing their own care, but by implication for coordinating care services in the
16 absence of effective coordinating technologies to mediate professional
17 boundaries.

18

19 Our findings provide a rejoinder to existing patient involvement literature (O'Hara
20 and Lawton, 2016; Ellins et al., 2012). We suggest that patients are central to the
21 coordination process, but that this role is heterogeneous, not limited to prescribed
22 decision-making processes and may entail a more active coordinating role in
23 repairing or making up for deficiencies in formal organisation (O'Hara et al 2018).
24 Patient involvement and empowerment are not straightforwardly produced, but
25 rather sit more comfortably with professional-practice groups whose knowledge

1 and expertise rests on accounting for the personal and social circumstances of
2 patients and service users, while other groups may be reluctant to engage or resist
3 these tasks. Our study suggests we cannot take for granted a direct correlation
4 between active involvement in the care process and increasingly positive
5 experiences of care. Indeed, our study found instances of patients' reporting
6 positive experiences whilst occupying relatively passive roles as boundary objects
7 and conversely, patients reporting negative experiences of being called upon to
8 express subjective wishes or exhibit agency as the coordination of care.

9

10 Active coordination and decision making clearly involves additional work, and
11 patients and family members were often surprised at this effort and frustrated by
12 the gaps they saw in inter-professional coordination. In other words, we can
13 consider patients and families as intrinsic to the translational work (Allen, 2014a)
14 of moving themselves across the health and social care system. This perhaps
15 suggests more consideration needs to be placed on preparing patients for their
16 boundary roles. Writing to propose a vision of the future of health services in
17 1988, Strauss and Corbin argued we should recognise that it is the ill and their
18 families who do the major work of managing chronic illness and therefore a new
19 relationship between acute care and the patient should be installed which takes
20 this into account. This study suggests we are still trying to find a way to address
21 this call.

22

23 **Conclusion**

24 Patient involvement literature argues that stimulating patients and families
25 involvement in the coordination of health and care systems will lead to

1 improvements in care quality. This study finds patients already making a central
2 contribution to the coordination process, but that the form of this contribution is
3 dependent on wider relations with and between agencies contributing to their
4 care. Active involvement is not an unequivocal 'good' but plays into the
5 professional politics and gaps in coordination within a health and social care
6 system under significant strain. This does not necessarily suggest ambitions to
7 further patients' involvement should be curtailed, but it does indicate that more
8 could be done to understand the implications of involvement activities at the
9 system level. As healthcare systems experience common challenges of stretched
10 resources and growing demand, the expectations placed on citizens when
11 adopting the role of the patient appears a pressing topic for contemporary debate.

12

13

14

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