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Patient and family perspectives in resilient healthcare studies: A question of morality or logic?

Abstract

Whilst interest in resilient healthcare (RHC) research has increased over the past five years, our understanding of the role of patients, families and carers in supporting system resilience remains limited (Berg et al, 2018; Laugaland & Aase, 2015). The extant empirical evidence for RHC has almost exclusively been undertaken from the perspective of staff. However, evidence is emerging suggesting that patients, families and carers impact on variability and outcomes within complex health systems, and as such could be regarded as co-creators of resilience (Schubert et al, 2015; O'Hara et al, 2018). Within health services research and improvement, engagement of patients and the public is widespread, with an ever building evidence base examining how, and in what ways such engagement should be done (Kirwan et al, 2017). Thus, as it grows as a discipline, there is no doubt that this 'moral' argument for the involvement of patients and families in RHC research will increase. However, in this paper we argue that whilst involving patients and families in RHC research clearly remains a moral imperative, it is also – and perhaps as importantly – driven by the logic of doing so. We view the integration of patient and family *perspectives* in RHC studies, as comprising two discrete, but not mutually exclusive approaches: i) Patient and family 'involvement' in RHC studies, as *co-creators of evidence*; and, ii) exploring and modeling patient and family 'functional activity' within systems, recognising their role as *co-creators of resilience*. We will discuss six case studies of RHC research, two that explore the role of patients and family activity within systems, and four that do not view patient and family activity as part of the system. Our aim is to demonstrate how without these perspectives, our understanding of work-as-done may be limited, and not account for variability introduced by these key actors within the system, that both supports, and compromises, the resilience of that system. In short, without understanding this variability we risk misunderstanding the resilience of our healthcare systems. Drawing on the case study examples, we present a planning support tool for the involvement of patient and family perspectives in RHC studies, which will provide practical guidance to support decisions about when, and how, to explore and document patient and family activity within systems. As key stakeholders in healthcare systems, patients and families should always be involved as co-creators of evidence in RHC studies. However, here we argue that for most healthcare systems, they are likely to additionally be co-creators of resilience.

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Introduction

Getting the bus to school – a tale of multiple perspectives?

Imagine for a moment, you have recently moved house and your 13-year old daughter needs a plan for getting to her new school on public transport. As a dedicated researcher, interested in the resilience of systems, you set to this task by poring over bus and train timetables, looking into the safety record of providers, speaking to drivers and others in the trade, and spending time observing the reliability of the possible transport options. At the end of this exhaustive process, you identify the best solution to this problem, and over the first few weeks of the new school term, sit back and observe the success or failure of the system you have proposed. Your performance measures include the cost of the travel arrangements, the timeliness of your daughter's arrival home, and no reported untoward incidents (from your daughter, the school, or the local newspapers). On this basis, after 6 weeks you conclude that you have devised an efficient and reliable system. It is true that you often don't speak to your daughter about the system (she is a teenager after all), nor read the local newspapers, but the system seems to be working okay, so why question it? It is only when your daughter's school calls one autumn morning to say that she has been continually late for the past week, that you actively seek out information from her about the travel arrangements.

When you do, you find out that she sometimes doesn't catch the first bus in the morning as there are often too many students for the available seats, meaning she has to catch an alternative that gets her in 10 minutes later. This problem, and the fact that the bus is regularly late in the mornings, has led to a friend's parent often stepping in to drive them to school, but due to heavy traffic, this 'work-around' regularly fails to get your daughter school on time either. In terms of the resilience of this system, through understanding the experience of the main protagonist – your daughter – you have uncovered information about unexpected variability in key functional activity and resource use, which affects our understanding of the performance and efficiency of the system. Further, you have uncovered hitherto invisible activity that might provide some resilience in the system. Put simply, you realise that your assumptions about how the system was working were to some extent false, and that this new information – with the added perspective of the 'transport user' – has illuminated activity that both supports, and challenges, the resilience of the system.

Focus of current resilient healthcare studies

Whilst this makes an interesting hypothetical story, what has it to do with resilient healthcare (RHC) studies? RHC has emerged over the past decade, as a key focus for understanding and improving the safety of healthcare services. RHC studies as a discipline emerged from a long tradition of resilience engineering, which aimed to approach system safety by describing the failures and successes of real-life work processes as closely related phenomena (Hollnagel et al, 2008). The RE literature as well as the RHC literature explain resilience as the ability or capacity of the system to adjust to changes or variations in the

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system, or in it's environment (Hollnagel et al, 2008; Righi et al 2015; Wears et al, 2015). Studies within the RE tradition, have naturally focused on staff working within systems, through which an understanding of such adaptations has been developed. The movement of this tradition into healthcare has arguably brought with it this same focus, and healthcare professionals are so far the primary 'lens' through which system resilience is modelled (Berg et al, 2018). However, we posit that the presence of patients and family members in healthcare makes it different to many other complex systems that have previously been the focus within RE studies (e.g. nuclear industry, oil industry). Indeed, patients and families will inevitably introduce variation to the system, and/or effectively 'dampen' the consequences of variation (O'Hara et al, 2018). Thus, it is this position within the centre of healthcare systems that provides support for the inclusion of patients and families as one of the key groups of stakeholders to include in efforts to model resilience.

The developing importance of the patient and family 'voice' in health service research

RHC studies sit within a wider tradition of health services research, in which patient and family involvement is now regarded as a key component (e.g. Kirwan et al, 2017; Shippee et al, 2013). This has in a large part been driven by the shift in health service policy and practice towards greater engagement of patients in their care (Chambers, 2017). Indeed, it is now accepted by research funders, scientific journals, and the wider healthcare community, that research should involve and engage patients, families and carers in the development, conduct and dissemination of research. Following this wider focus, the field of RHC studies has therefore begun to ask how patients and families should be involved in research, but to date, where the patient or family 'voice' has been evident, this has arguably been undertaken from an ostensibly 'moral' imperative, manifested in ensuring the robustness and meaningfulness of the research purpose, the research questions asked, and the inferences made from the data.

Moving beyond the moral imperative

There is increasing empirical evidence, from both RHC studies, and wider health services research, that patients, families and carers are undertaking activity that both increases, and reduces, the variability of functional activity within healthcare systems (Furniss et al, 2014; Fylan et al, 2017; Laugaland et al, 2014). Despite this, their perspective has been almost entirely absent from the burgeoning RHC studies evidence base (Berg et al, 2018). At this point, it is important to clarify what we mean by patient and family 'perspectives' and their integration within RHC studies. We have thus far used the term 'perspective' to describe the range of contributions that patients and families can bring to RHC studies. However, for the purposes of this paper, we further delineate the notion of 'perspective' into two discrete, but not mutually exclusive approaches: as co-creators of evidence, and as co-creators of resilience. Patient and family *involvement* in RHC studies represents the 'moral' imperative – i.e. the importance of involving those using healthcare services as key stakeholders in the research agenda. In this approach, patients and families

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are viewed as part of a research team, co-creating evidence about the resilience of healthcare systems. As mentioned above, patient and public involvement (PPI) and co-production have a long history in health services research, with a wealth of associated methods and frameworks to guide them (e.g. Greenhalgh et al, 2019; Bate & Robert, 2006; Robert et al, 2015).

Exploring and modeling patient and family *activity* within systems, is the second of these two approaches. This approach recognises the role of patients and families as active agents in systems that introduce variability, and undertake functional activity that contributes to resilience. In this approach, patients and families are seen as co-creating resilience. This is conceptually very different to the first approach, but as mentioned earlier, until recently has been largely ignored by those undertaking RHC research studies. In this paper, we suggest that integrating the views and experiences of patients, families and carers in exploring the resilience of healthcare systems, is not simply driven by morality. We argue that whilst the moral argument to represent the views and experience of those funding and receiving public services will always remain, without accounting for the activity undertaken by patients and families, and the variability (both desirable and undesirable) that this introduces, we risk making erroneous assumptions about the resilience of our healthcare systems.

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Case studies

In this next section, we will elaborate on these arguments by examining six selected case studies from the existing RHC literature. We sought specifically to understand the extent to which studies have explored and documented the functional activity that patients and families undertake within healthcare systems, that influences the resilience of the system under examination. The choice of case studies was based on a recently published integrative review of 22 RHC studies (Berg et al, 2018). The six case studies were purposively sampled to represent three key types of RHC research: i) RHC studies that we argue have appropriately explored patient or family activity within the system; ii) RHC studies that have not explored patient or family activity within the system, but we argue should have; and, iii) RHC studies that have not explored patient or family activity within the system, and we argue this is appropriate. We ensured that the selection of these studies was undertaken to include representation from both medical and surgical specialties.

It is important to note that these categorisations can only be made on information contained within the published papers. Thus, we do recognise that authors of these papers may have undertaken additional work not included in the publication, or made decisions that we are not party to. We return to this issue later in the paper. The selected case studies are detailed in Table 1 including information on authors, inclusion of patient activity, setting, topic, design, methods, sources, and analysis.

i) RHC studies that have appropriately explored patient or family activity within the system

Our two chosen case studies in this category are papers describing RHC studies that undertook to understand the activity that patients and/or families undertake within their modelling of the system and its' variability. Brattheim et al (2011) explored the characteristics and sources of process variability in a surgical care process that crossed professional, service and institutional boundaries. They observed the abdominal aortic aneurism surveillance programme across three hospitals, interviewing both patients and HCPs documenting variations related to sequence, activity, place, and time. They found that patient actions resulted in a number of instances of unintended variation in processes associated with other activity such as patients preferring to have their CT exams/tests at private institutes, leading to non-planned, extra information processing, or patients seeking to reschedule their exams to the same day as the clinical consultation, leading to delays in sharing of the surgical opinion with the patient. Patient preference has long been known to be a source of variation in processes and outcomes (e.g. Robinson & Thomson, 2001), however, this study demonstrated unintended process variation caused by the patient actively influencing the system.

Laugaland et al (2014) explored the functions and variability of hospital discharge of older patients using observations and conversations with patients, family members, and HCPs involved in the discharge process. They found that the hospital discharge processes across seven medical and surgical wards was comprised of an interwoven set of ten common functions. These functions constituted the daily practices of discharging older patients from the hospital to community healthcare services in which multiple stakeholders were involved including the patient and family members. Several of the ten functions had the patient and family members as active agents in decision-making and knowledge-sharing activities in the discharge process. The study demonstrates that active involvement of the patient and family members impacts on the precision of the discharge processes and the perceived outcomes of them. Active patients with comprehensive knowledge of their own situation, diagnoses, and medication furthermore appeared to affect the degree of information and knowledge sharing with HCPs, thus, effectively 'dampening' unwanted variation in functional activity, and increasing the likelihood of desired outcomes.

ii) RHC studies where not exploring patient or family activity in the system was inappropriate

Our two chosen case studies in this category are papers describing RHC studies that did not report actively seeking to capture the patient or family activity within their system under examination. We argue here that not capturing this activity was inappropriate. Both studies set out to understand the complexity of clinical micro-systems within hospital settings, the sources of variation, and the resilience of the processes described. Ross et al (2014) sought to describe the provision of inpatient diabetes care, how resilience is created, and how it breaks down, using the Critical Decision Method (Hoffman et al, 1998) based on interviews with healthcare professionals across the service.

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Table 1 – Case Study Descriptions

Authors	**Patient activity modeled?**	**Setting**	**Topic**	**Design / methods**	**Sources**	**Analysis**
Laugaland et al, 2014	Yes	Medicine, and surgery	Variability in discharge processes	Case studies/ observation, conversations	Patients, HCPs, carers	FRAM
Brattheim et al, 2011	Yes	Surgery	Variability in abdominal aortic aneurysm surveillance program	Case studies/ observation, interviews	Patients, HCPs	Work pattern scenarios, content analysis
Ross et al, 2014	No	Medicine	Resilience in inpatient diabetes care	Qualitative study/ interviews, Critical Decision Method	HCPs, managers	Thematic
Dekker et al, 2013	No	Surgery	Complexity of obstetric interventions	Qualitative study/ observation, interviews, Critical Incident Technique	HCPs	Thematic, theory-based
Patterson & Wears, 2015	No	Pharmacy at medical ward	System adaptation to intensified demand	Observation	HCPs	Thematic, theory-based
Nysson & Blavier, 2013	No	Robotic surgery	System adaptation to introduction of robotic surgery	Observation, experimental design	HCPs	Thematic, quantitative (not described)

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In their study, the authors found a number of instances where variation in processes likely resulted from patient characteristics, or patient choice. For example, variation in patient knowledge or compliance creates variation in the service provision, through increasing workload due to the need to provide support for patient education. Most variation however, was found to be associated with the infrastructure of the diabetes inpatient service provision, and other varying contextual factors such as skill mix and staff availability. Dekker et al (2013) aimed to understand the complexity of clinical practice in obstetrics, and in particular, compliance with best practice guidelines, using interviews with healthcare professionals and observations of practice. They sought to understand how, in a system like obstetrics, which offers “a large number of ambiguous situations” and often operates with “unclear definitions of responsibilities and accountabilities” (Dekker et al, 2013; p.2), resilience emerges in complex situations. They found obstetrics to be a complex, rather than complicated system, that cannot be reduced through simple categorization of ‘stable states’ such as the distinction between normal and non-normal labor. Embracing this complexity, they argue, through enhancing the positive aspects of diversity, should support emergence of resilience in complex situations.

In both these studies, whilst the authors seem to recognize the variability introduced by patient characteristics, they did not seek to explore the potential role of patients (or mothers) and families as partners in dampening unwanted variability, or increasing the likelihood of desirable safety outcomes. For both of these clinical settings, evidence would suggest that this is an omission. For example, in diabetes care, self-management of the condition by patients in hospital settings is now recommended (NHS Diabetes, 2012). Indeed, emergent evidence suggests that self-management of diabetes by inpatients may support better administration of insulin, coordination of glucose monitoring, and appropriate nutrition (e.g. Mabrey & Setji, 2015). With regards to maternity and obstetric services, these are arguably one of the key health services where currently the users of the service are actively encouraged to engage in decisions about care and treatment (e.g. WHO, 2016). Further, evidence is accumulating that suggests that mothers and birth partners often engage in a variety of ‘safety work’ across pregnancy and labour, including self-monitoring during pregnancy, self-diagnosing, and navigation of different services (Mackintosh et al, 2017), as well as advocacy for themselves and their babies, and ‘speaking up’ about more immediate safety concerns (Rance et al, 2013).

iii) RHC studies where not exploring patient or family activity in the system was appropriate

The two final case studies represent examples of papers that do not report capturing the patient or family activity within the system. However, in this category, we argue that not capturing this activity was appropriate. Nyssen and Blavier (2013) describe a largely observational study of robotic surgical techniques within laparoscopy procedures. The authors recorded verbal communication between surgeons, and sought to interpret these communications to understand how surgeons adapt to the introduction of robotic surgery in operating rooms, to ensure the safety of the laparoscopic procedure. The system under

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observation was limited to the operating theatre, and the staff within the theatre during the laparoscopy. Patterson and Wears (2015) sought to understand the adaptations evident within a hospital-based paediatric oncology/ haematology pharmacy, using observations and interviews. This unit was physically embedded within the paediatric haematology and oncology ward under observation, and prepared and dispensed medications, as well as chemotherapy. The pharmacists and pharmacy technicians interacted with the nursing and medical staff, but appeared removed from direct patient contact.

Within both of these cases, it is arguably clearer that the patient and family would have minimal opportunity to affect system resilience, outside of the traditional focus on patient characteristics introducing variability in the success of functional activity. For example, in the first case, the patient is unconscious for the entire period which the system boundary represents, whilst in the second, they are absent from the service or team entirely. Thus, in both cases, there is almost no opportunity for the patient or family to have active agency within the system boundaries. It is factors such as this, we believe, that must be considered when making decisions about whether to model patient and family activity in explorations of system resilience. In the next section, we describe a 'planning support tool' that supports researchers to be systematic in their choices about including and reporting the perspective of patient and families, whether this is *involvement* in the research itself, or through modelling *functional activity* that is introduced into the system..

A planning support tool for integration of patient and family activity in RHC studies

Having taken a critical look at six case studies, we propose a planning support tool (Figure 1), to aid researchers in decisions about when, where and how to integrate the perspective of patients, families and carers in RHC studies. The tool consists of a flowchart with three main decision stages related to agency and system boundaries.

1. *Does the patient have active or potential agency within the boundaries of the system?*

Most RHC studies are conducted within system boundaries that are more or less specified. Defining the system boundaries of a RHC study might be quite straightforward, as in the robot-surgeon system studied in Nyssen & Blavier (2013). Defining the boundary might also involve complexity and interconnections between sub-systems, as in the surgical care process transcending multiple institutions and professional boundaries studied in Brattheim et al (2011). To be able to assess patient agency in a system we suggest that RHC studies first need to reflect on the degrees of interactive complexity in the system (Laugaland & Aase, 2015).

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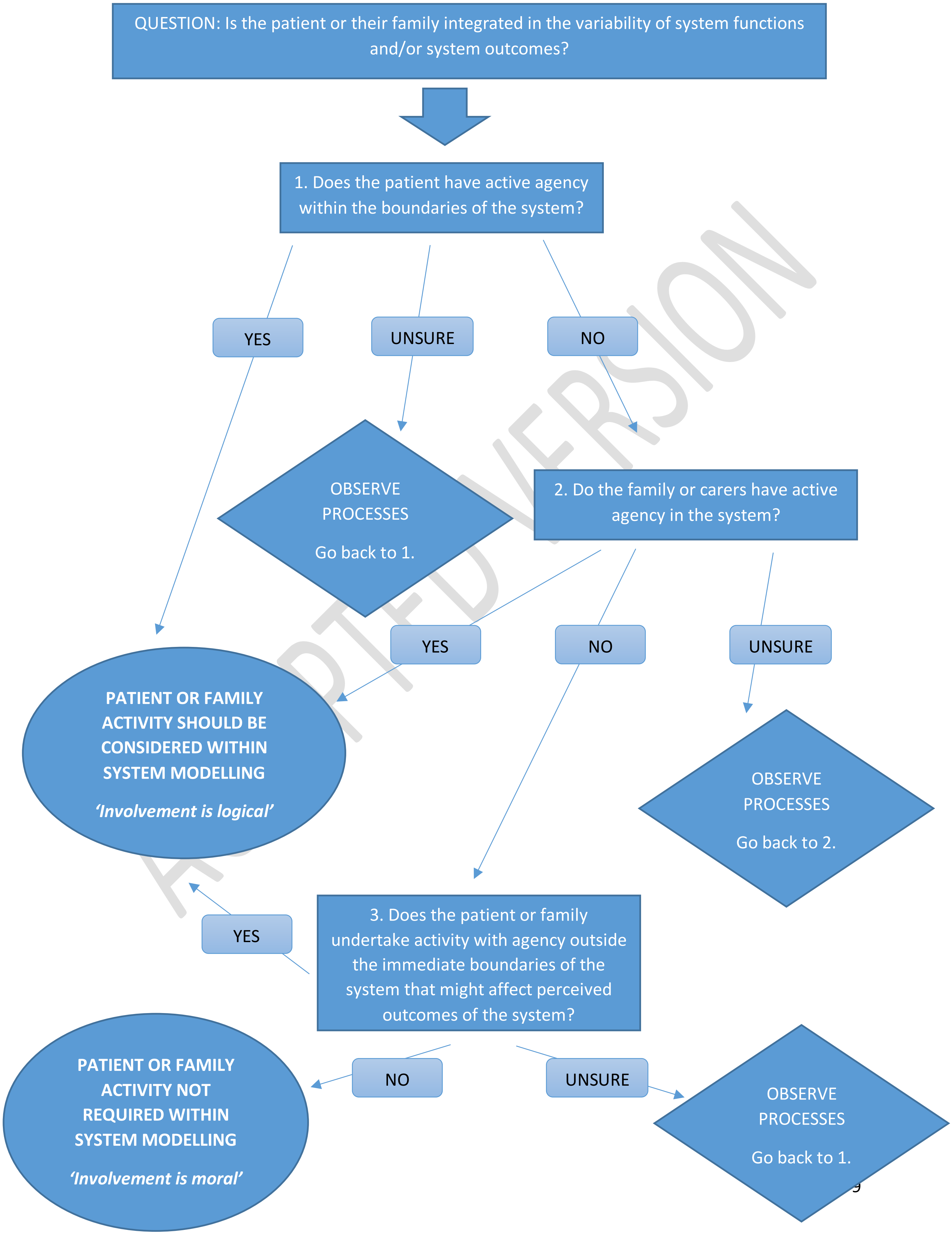
Figure 1: Planning support tool for integration of patient and family activity in RHC studies



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Our advice is not to aim at clear-cut system boundaries but instead to focus on possible interconnections between sub-systems (or functions) and/or stakeholders such as the patients. Just as functional activity is interdependent in complex systems, very often the success of individual activities may rest on interdependencies with patients or families to support better outcomes or reduce unwanted variation, as described by Mackintosh and colleagues (2017) in their study of help-seeking in acute perinatal events. Patients have an active role in the vast majority of healthcare processes such as medication management, admission and discharge processes, treatment of chronic health conditions, or in diagnosis related tasks. However, in some RHC studies in which the system boundaries are restricted to surgical or other clinical processes in which the patient is unconscious, no active patient agency is present. Other healthcare processes might involve stakeholders that are conducting tasks without direct patient contact such as laboratories. The robot-surgeon study of Nyssen & Blavier (2013) and the pharmacy study of Patterson & Wears (2015) appear as RHC studies in which patients have no active agency and therefore_the omission of patient activity seems appropriate.

<u>Example decision aid questions for stage 1:</u>

- Is the patient awake, conscious and have capacity to act?
- Does the patient or family provide information on which clinical decisions are made?
- Does the system cross boundaries (services, wards, people) in which the patient or family might take on a knowledge broker role?
- Is the patient part of a wider healthcare team with specified roles for their care such as self-management at home, self-administration of routine medication within wards?

2. *Do the family or carers have active agency in the system?*

Where the patient does not have active agency within the system boundaries, a second question has to be about the degree to which their family or carers do. For example, it has been proposed that families may buffer variability in systems that present structural gaps, through acting as a knowledge broker between settings (O'Hara et al, 2018). Even within services, families arguably have an important role in reducing variation in activity through supporting patient history taking, escalating concerns (Albutt et al, 2016), or providing direct care. Indeed, emergent evidence suggests that even in services where very often the patient may lack capacity, such as intensive care units, families should be regarded as partners in care, rather than simply as active agents in shared decision-making (e.g. Azoulay et al, 2014; Olding et al, 2016).

<u>Example decision aid questions for stage 2:</u>

- Do family or carers provide information on which clinical decisions are made?
- Does the system cross boundaries (services, wards, people) in which the family might take support movement of information to support the patient?

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- Are the family or carers part of a wider healthcare team with specified roles for their care such as self-management at home, self-administration of routine medication within wards?

3. Does the patient or family undertake activity with agency outside the immediate boundaries of the system that might effect perceived outcomes of the system?

If it is established that neither the patient, their family or carers, have agency to act within the boundaries of the system under exploration, a final question should be asked. This question arguably has two component parts: first, to what extent does the patient, their family or carers undertake activity immediately outside the boundary of the system being explored, that might effect the perception of the success of the outcomes of that system; and, second, to what extent are the patient and family likely to differ in the assessment of the outcomes of the system under exploration, from those involved in the modelling of that system? Let us examine these issues in order.

Whilst we argued in the earlier examination of the case studies, that two of our case studies (Nyssen & Blavier, 2013; Patterson & Wears, 2015) are appropriate in not seeking to explore activity introduced by patient and families, in this final question, it is right to revisit these assumptions. This is particularly important given that our categorization can only be accomplished based on the available data reported within published papers. For example, in the paediatric oncology pharmacy system described by Patterson and Wears (2015), they state that there has not been a serious adverse event in the pharmacy for some time. This may indeed be the case. However, given that we know from other evidence, patients and families receiving chemotherapy can identify problems with medication administration, and are likely to be in a position to ameliorate them (e.g. Schwappach and Wernli, 2010), to what extent can we be sure that the lack of medication error is not, at least in part, due to patients or families effectively diverting administration or prescribing errors?

The second part of this final question also requires us to revisit our assumptions. Laugaland et al (2014) in their examination of discharge for older adults, concluded that “various stakeholders had different concerns and used different measures to evaluate the degree of successful hospital discharge functioning….[implying that] the assessment of acceptable, successful outcomes depends on the focus of the stakeholder groups” (p.13). If we extend this logic to the surgical environment described by Nyssen & Blavier (2013), we might query the degree to which the assessment of outcomes following the introduction of robotic surgery, include patient-reported outcomes? As Nick Black noted in 2013, in his discussion on the potential for patient reported outcomes to transform how we understand quality in healthcare, patient reports of clinical outcomes effectively avoid observer bias (Black, 2013), which occurs when asking clinical staff to measure their own outcomes, as happens in the measurement of surgical complications. Whilst we cannot be sure that a patient and family perspective may have altered the assessment by Nyssen and Blavier (2013) of the resilience of the communication between surgeons following the introduction of robotic surgery, it is a useful exemplar of the need for researchers to ask these questions

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about the assessment of outcomes of a system, by stakeholders who sit just outside the boundaries of that system.

Example decision aid questions for stage 3:

- How are measurements made as to the effectiveness of the system?
- Should patients and families judge the effectiveness of the system?
- Does the patient undertake any ‘invisible’ activity to achieve successful outcomes?

It is important to note that assessments of the appropriateness of researcher decisions regarding the modeling of patient and family activity are difficult to be done retrospectively. For this reason, based on the published papers, we categorised Nyssen and Blavier (2013) and Patterson and Wears (2015) as appropriately omitting patient and family activity within their examination of resilient healthcare systems. Rather, we present this planning support tool for use by researchers to prospectively consider these three key questions, to support the design and methods used within RHC studies.

Appropriate methods

The three main stages of our decision aid require a certain level of advance knowledge of the system to be able to make the right decisions regarding the integration of patient and family activity in RHC studies. This is depicted through the “Observe processes” diamonds within the flowchart. By advance knowledge of the system, we mean that the researcher should map the main processes of the system through, for example, a pilot observational study, conversations or interviews with key informants of the system, or by video recordings.

Methods for exploring and documenting patient and family activity in RHC studies (i.e. ‘involvement is logical’)

Exploring and documenting patient and family activity within RHC studies should use observation as a primary method (Nemeth and Herrera, 2015). Observational research will allow the researcher to study the patient and family activity as it is actually performed. System modelling tools such as the Functional Resonance Analysis Method (FRAM: Hollnagel, 2012), flowcharts, process mapping and work domain analysis could strengthen the observations by analysing and visualising patient and family activities in the processes. Process visualisations could furthermore act as artefacts to facilitate discussions with patients and families to validate and detail the process descriptions.

Process descriptions of patient and family activity in RHC studies could also be driven by various other methods such as interviews, focus groups, video and audio recordings, and appreciative inquiry. Indeed, the core of RHC methodology is the application of diversity, and the use of methodological triangulation to enhance the credibility of findings, and this applies equally to the study of patient and family perspectives (Berg et al, 2018). Further, participatory research approaches, such as experienced-based co-design inspired by service

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design theory and practice can be applied in the study of patient and family perspectives in RHC to bring the different system users together and enable user-centered system modelling (Donetto et al., 2015). Given that much of 'healthcare' in its broadest sense, can take place outside traditional healthcare system architecture, one way to explore the role of patients and families in system resilience would be to shadow a patient through their care pathway or care experience. One method for this might be using 'go-along' interviews (Carpiano, 2009; Miaux et al, 2010; Hardicre et al, 2018). This method is person-centred and interactive, and seeks to explore lived experience, within changing contexts in real time, through undertaking an interview with someone whilst they experience a phenonmena. This method can be a powerful way of uncovering otherwise unarticulated feelings, memories or opinions through exploring a phenomena *in situ*.

Methods for patient and family involvement in RHC studies (i.e. 'involvement is moral')

As previously mentioned, RHC studies sit within the broader health services research field in which the involvement of patients, family and carers in research activities has rapidly developed over the last decade (Greenhalgh et al, 2019). Methods for such involvement range from highly active approaches such as patients or family members being fully integrated co-researchers or co-leading service design processes, to more passive approaches such as reporting of adverse events or being members of user panels. For RHC studies the same range of methods are valid, with the specific aim of using patients and families to explore, understand, and model the system processes under examination.

Despite the call for more active involvement of patients and family in health services research in general, and in the prevention of healthcare-related risks more specifically, there is still insufficient evidence about the best methods for proactive engagement, roles, and how to utilize the untapped potential (Domecq et al, 2014; Pomey et al, 2017). Yet, several frameworks and resources exist as to the planning and accomplishment of involvement in research, for example the NIHR Patient and Public Involvement handbook in the UK (www.nihr.ac.uk) and the CIHR Strategy for Patient-Oriented Research in Canada (www.cihr-irsc.gc.ca). These frameworks offer substantial support for researchers to plan the best possible involvement of patients and families as partners within RHC studies. They also provide guidance regarding some of the additional considerations that researchers need to be mindful of, regarding ethical issues of supporting patients and the public in being equal partners within research, guidance on compensation, and training for involvement in research processes, as well as ways to avoid the ever present spectre of tokenistic engagement.

Summary and conclusions

In this paper, we have argued for the need to move beyond the assumption that engaging with patients and families in RHC studies is simply based on an ostensibly 'moral' imperative. Using a series of six case studies, we have been able to demonstrate the

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circumstances under which patients and families may, or may not, undertake functional activity or introduce variation that may influence the resilience of healthcare systems. Based on this exploration, we presented a tool to support researchers in making decisions about whether patients and families should be part of an exploration and documentation of *activity* undertaken within a system, or whether they should be *involved* in the research as part of co-creators of evidence. Finally, we presented methods that researchers might want to use to achieve these different aims.

The RHC literature, and indeed the wider health services research literature, is well used to exploring and modeling how variation is introduced by patients and families, in terms of the functional activity and process flow. However, what has yet to be acknowledged within RHC studies to any great extent, is the reduction in, or dampening of variation, that may occur as patients and families interact with our healthcare systems. Indeed, as Patterson & Wears (2015) note, the success of adaptations "…makes dysfunctional work systems and practices appear to be performing better than they actually are" (p.45). In this paper, we have argued that this same principle might often apply to adaptations by patients and families, underlining the need for researchers to ask themselves before observing systems, who are the key actors that should be involved in our modeling of a healthcare system. We have presented a tool to support these decisions by researchers, supported with exemplars from the literature.

The logic of including the patient and family perspective in RHC studies, does not supersede the moral argument for research to be co-produced with patients, families and healthcare professionals, and for it to be meaningful to, and impactful for patients and the public. To be clear – this is not an either/or decision for RHC researchers. Indeed, it is arguable that *all* RHC studies should, as a minimum seek to engage with patients and families as key stakeholders in co-creating evidence about healthcare system resilience. However, we believe that the involvement of patients and families in understanding the resilience of healthcare systems goes beyond this moral imperative. Indeed, given the likelihood of the next decade witnessing the movement of healthcare out of hospitals and into our communities and homes, with the concomitant increase in self-management and self-care, the artificial boundaries between patient as receiver, and staff as provider of healthcare start to fall away. In this new healthcare paradigm, we shall no longer be able to separate "us" and "them", being in effect, all 'in it together' within a most complex and distributed system. Thus, both for today's and tomorrow's researchers, modelling healthcare systems without capturing the perspective of patients and families is likely to be, more often than not, illogical.

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