Six mechanisms behind carer wellbeing effects: A qualitative study of healthcare delivery

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ABSTRACT

Health and care services *for patients* may improve or harm the wellbeing of their *family carers*. Formal consideration of these effects (also known as spillovers) in decision-making is advocated, but, to date, little is known about how they occur. This paper presents the first empirical study to determine the mechanisms by which health and care services affect family carers' wellbeing. The study focused on three major health conditions: dementia, stroke, and mental health. Focus groups and interviews were conducted with 49 purposefully sampled care professionals and family carers in the UK between December 2016 and September 2017. Transcripts were coded and analysed thematically, using descriptive accounts and an explanatory account. The analysis generated six over-arching mechanisms by which health and care services affect family carers' wellbeing, through: (i) *information* (degree to which service delivery informs and trains family carers); (ii) *management* of care (shifts of responsibility for care between formal and family sectors); (iii) *patient outcomes* (services changing patient outcomes); (iv) *alienation* (feelings of alienation or inclusion created by service delivery); (v) *compliance* (barriers to patients complying and engaging with services); and (vi) *timing or location* (changes in the timing or location of services). Each mechanism was associated with sub-themes relating to both positive and negative spillovers on the family carers. The six mechanisms can be summarised with the mnemonic 'IMPACT'. The IMPACT mechanisms may be useful in designing and evaluating services to optimise the wellbeing of carers as well as patients.

1. Introduction

Family carers are a vital health, social and economic resource across the world (Pickard, 2015; Carers, 2018; Family Caregivers Allianc, 2016; Hu and Ma, 2018). However, many carers experience significant physical, psychological, financial and social strain from their caring role (Pinquart and Sorensen, 2003a; Schulz and Beach, 1999; Atkin and Twigg, 1992; Carmichael and Charles, 2003; Ross et al., 2008). While clinical trials have built up an evidence base on the effects of healthcare services on patient outcomes, very little attention has been paid to the health and wellbeing impacts of patient services on family carers (Al-Janabi et al., 2016). Attention to these 'family carer spillovers' is important for at least two reasons. First, it provides a more comprehensive picture of the effectiveness and cost-effectiveness of health and care services. Second, it can help ensure services are delivered to optimise

the wellbeing of both patients and carers. To better identify and measure family carer spillovers, an understanding of the mechanisms by which patient services can impact on carers' lives is needed.

A psychological starting point for understanding spillovers of services on family carers is Pearlin's stress model (Pearlin et al., 1990). In the model, the degree to which family caring contributes to stress depends on the patient's health problems and dependency on the family carer (primary stressors), as well as potential conflicts between informal care and other roles in the carer's family, work, and relationships (secondary stressors). Many studies have demonstrated links between these stressors and the carer's outcomes. For example, studies have variously showed that family carers experience higher stress and worse outcomes when, for example, patients experience a decline in cognition or mobility (Newbronner et al., 2013; Donaldson et al., 1997; Clipp and George, 1993), incontinence or behaviour problems (Newbronner et al.,

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2013; Pinquart and Sorensen, 2003b), or when the carer has to juggle multiple roles (Awad and Voruganti, 2008).

Pearlin's model focuses on the stressful aspects of caring for a family member, but it is quite possible to extend the logic to think through how patient services might impact on carer stress. If a drug for a patient slows the patient's cognitive decline, one would expect fewer demands on the carer and therefore less stress. Conversely, all else equal, if social care services for the patient are cut, the family carer may have to step in resulting in more informal care, which may conflict with other roles in the carer's life and increase the strain they are under. While such spillovers are plausible, few studies have collected data on the effects of patient services on both patient and carer (Christakis, 2004). Where data has been collected, the findings can be unexpected. An evaluation of a model of stroke follow-up care, for example, unexpectedly found that the intervention delivered health benefits to carers (through reducing their depression), rather than patients (Fens et al., 2014). Although no reason is provided, this may have been due to increased social activity levels in patients (Fens et al., 2014).

Within economics, the concept of the caring externality (Culyer, 1971) is helpful in understanding the potential for family carer spillovers. The caring externality describes the idea that the wellbeing of one individual is positively influenced by the wellbeing of (or services received by) a second individual. This idea that individuals' 'utility functions' can be considered to be interdependent is particularly pertinent to family carers (Prosser et al., 2012). For family carers, there is a dual spillover as family carers may get disutility both because they care *about* and they care *for* the patient (Bobinac et al., 2010, 2011), i.e. both witnessing a loved one's poor health and the impact this has on caring responsibilities may reduce the wellbeing of family carers. In the same vein, a treatment that improves the patient's health has the potential to improve the wellbeing of the carer, both because it may reduce the carer's distress about the patient's health and because less informal care is needed. There is a growing literature on caring externalities (Jacobsson et al., 2005; Hurley and Mentzakis, 2013) that suggests externalities can be particularly strong in the context of family caring relationships (Prosser et al., 2004; Basu et al., 2010; Konig and Wettstein, 2002).

Previous conceptual work provides a further starting point for thinking about the mechanisms behind family carer spillovers (Al-Janabi et al., 2016). This suggests that patient services may affect carer wellbeing, for one four reasons; (i) the service changes the patient's outcome, affecting the level of carer distress; (ii) the service changes the patient's outcome, affecting the scale and scope of informal care; (iii) the service directly changes the scale or scope of informal care; and (iv) the service changes the lifestyle or attitudes of family carers.

The objective of this study was to empirically determine mechanisms by which health and social care services affected family carers' lives (see Table 1). A deliberately broad view of health and social care services was taken, to encompass not just specific interventions (such as drugs), but also the way in which interventions and services are organised and delivered ('service delivery') since service delivery also has important resource consequences (Meacock, 2019) and may impact on carers. The focus was on services in three clinical areas: dementia, long-term mental illness and stroke. These areas were chosen to cover major conditions (McCrone et al., 2008) associated with substantial family care (Neubauer et al., 2008) and different challenges for carers, relating

to disease progression (Lefley, 1996), service availability, and the way in which informal care is organised in family networks (Atkin and Twigg, 1992). For example, evidence suggests caring for someone with dementia is particularly stressful (Clipp and George, 1993; Pinquart and Sorensen, 2003a), with challenges related to the care recipient's movement, memory loss, incontinence and the progressive nature of the illness Pinquart and Sorensen (2003a). Mental illnesses, such as schizophrenia, can bring wide-ranging negative impacts on families such as shame and guilt (Pinquart and Sorensen, 2003b; Awad and Voruganti, 2008; Gallagher and Mechanic, 1996). Conditions associated with physical morbidity, for example stroke (Brouwer et al., 2004), may be particularly labour-intensive for the carer.

2. Methods

A qualitative study comprising focus groups and interviews in the UK was used to investigate family carer spillovers in dementia, mental health and stroke. Focus groups were used to get breadth on the topic (Ritchie and Lewis, 2003), by bringing a range of individuals together who could develop ideas relating to family carer spillovers. Interviews were used to investigate specific experiences in more depth (Ritchie and Lewis, 2003) and enabled participants who did not attend one of the focus groups to be included.

2.1. Sampling

Two broad groups of participants were included: family carers and care professionals. Family carers brought personal experiences of spillovers, while care professionals brought their broad experience of services and contact with a range of patients and family networks. Purposeful sampling (Ritchie and Lewis, 2003) was used to ensure carers and care professionals in a range of circumstances across all three clinical areas were involved.

Family carers were recruited to focus groups with the assistance of charitable organisations in the three clinical areas. These organisations advertised the study to local members, with the objective of recruiting carers in different roles. Additionally, to gain responses from carers not affiliated to a charity, a number of carers were approached for interview from those who consented to being re-contacted as part of a recent survey of family carers' quality of life (McLoughlin et al., 2018). These individuals had previously taken part in the nationally representative UK-wide Family Resources Survey and indicated that they provided care for a family member. Carers were recruited to the focus groups and interviews with the aim of ensuring sampling variation in relationship to the patient (spouse, parent, and adult-child), gender and age.

Care professionals were recruited with the help of NHS Trusts in the West Midlands (England). These organisations advertised the study on their research sites and used their professional networks to identify interested parties. To ensure all key groups were represented, a number of one-to-one interviews were conducted. Interview participants were identified through contacts within the project advisory group. Purposeful sampling was used with the aim of ensuring representation across primary, secondary and tertiary health care, social care and the charity sector, as well as different professions. Sampling continued until (i) focus groups had been conducted in each clinical and role group; (ii) key groups of family carers and care professionals had been represented

Table 1
Conceptualisation of family carer spillovers in this study.

Cause of spillover	Mechanism for spillover	Outcome of spillover
Health and social care services targeted at patients with dementia, mental health or stroke. This includes both specific interventions and the way in which services are organised and delivered.	Social phenomena that give rise to a causal relation between the service and carer outcome.	Impact on the quality of life of the family carer, where quality of life encompasses social, physical, emotional and financial aspects. 'Family carer' includes those close individuals affected by a patient's illness or patient's service use, regardless of whether they self-define as a 'carer'.

Fig. 1. Focus group exercise to identify links between patient services and carer wellbeing. Circles indicate pre-defined outcomes (Brouwer et al., 2006; Deeken et al., 2003; Al-Janabi et al., 2008) and the rectangle is example of patient intervention or aspect of service delivery. Note: Intervention prompts (cards) were: medication, psychological intervention, rehabilitation, complementary/alternative therapy, and social care. Service delivery cards were: inpatient care, transfers between services, involvement of family, funding/organisational changes, and location of care. Participants were also provided with blank cards.

through a focus group and/or interview; and (iii) thematic saturation had been reached as judged through field notes.

The study was reviewed and approved by University of Birmingham's ethical review committee (14–1444) and the NHS Health Research Authority (IRAS 206161).

2.2. Conduct of focus groups and interviews

Separate focus groups were conducted in dementia, long-term mental illness, and stroke. Focus groups were organised in this way to maximise the benefit of participants' clinical expertise. Focus groups were also conducted separately for family carers and care professionals to avoid family carers feeling inhibited talking about experiences of service delivery. The focus group began with introductions and a brief discussion of the way in which providing family care affected quality of life. In this first phase, participants were invited to identify any links between patient services and aspects of a carer's quality of life, using cards (Fig. 1). Eight domains of life and ten broad categories service delivery were identified in advance (Fig. 1). This was done to help the participants to focus on identifying any links between patient service delivery and impacts on the carer's life. The eight domains of carer life were based on a synthesis of studies on carer quality of life (Brouwer et al., 2006; Deeken et al., 2003; Wittenberg et al., 2013; Al-Janabi et al., 2008). The cards were based on service guidelines for the clinical areas, and refined through the initial interviews and focus groups. Participants were also encouraged to identify any additional services or domains of life affected during the focus groups. The resulting chart was then used to stimulate discussion with participants about the way in which different services affected carers' lives. The second part of the focus group concentrated on links between service delivery and carers' quality of life. As before, participants first matched cards about service delivery (e.g. 'transfers between services') to aspects of the carer's quality of life. This was followed by a structured discussion about the

way in which service delivery affected carers' lives. The topic guide is shown in Appendix 1.

The interviews had the same broad objective as the focus groups. However, the discussions focused on the services where participants had particular experience. The chart shown in Fig. 1 was used to facilitate discussions, although no cards were used.

Focus groups were conducted in meeting rooms at NHS trusts and charities. Interviews were conducted at workplaces or home addresses. Family carers received a £15 voucher. All interviews and focus groups were digitally recorded and transcribed verbatim. Field notes were written after each focus group and interview to capture salient points and aid reflexivity (Ritchie and Lewis, 2003). HA led the focus groups, conducted the interviews and wrote interview field notes. CM contributed to the focus groups and wrote focus group field notes.

2.3. Data analysis

A grounded theory (Strauss and Corbin, 1990) approach was used to generate new analytical categories to explain the mechanisms behind family carer spillovers. The analysis process started with a subset of transcripts being 'open coded' (Coast et al., 2017) by all members of the research team, assisted by the lay advisory panel to identify emergent ideas about *how* spillovers were generated. The open codes were then used, in combination with the field notes, to create a coding tree, linking interventions and service delivery to family carer outcomes (Appendix 2). The coding tree was used in the 'axial coding' (Strauss and Corbin, 1990; Coast et al., 2017) of three transcripts. Discrepancies among team members in coding were resolved through discussion and the coding process adjusted accordingly. The final coding tree was then applied to the full set of transcripts using Nvivo Plus v11.

Following coding of the transcripts, data were organised and analysed in descriptive accounts (Ritchie and Lewis, 2003; Coast et al., 2017) by clinical condition. This involved, initially, listing all coded passages under each relevant code, to begin to thematically reorganise data (Ritchie and Lewis, 2003). Following this, a record was created of the meaning of quotes individually and collectively under each code. These notes helped to chart links between codes and generate 'higher-order' themes. These higher order themes were broader and more interpretative than the individual codes (Miles and Huberman, 1994) as the analysis shifted to understanding the general mechanisms by which patient services affected family carers. The final stage was to rearrange the coded material under these mechanisms (higher-order themes) in the form of a single explanatory account (Ritchie and Lewis, 2003). This explanatory account spanned the three conditions and used quotes much more selectively to explain the range of positive and negative spillovers that arose from each mechanism.

3. Results

7 focus groups and 10 one-to-one interviews were conducted with 49 participants in total; 25 care professionals and 24 family carers (Table 2). Focus groups and interviews were conducted between December 2016 and September 2017. Focus groups lasted an average of 1hr 30 min and interviews lasted an average of 1 h.

The findings below summarise the explanatory account. Six overarching mechanisms were identified to explain how service delivery positively and negatively affected family carers' wellbeing. These mechanisms are: (i) 'information'; (ii) 'management of the care'; (iii) 'patient outcomes'; (iv) 'alienation' (v) 'compliance'; and (iv) 'timing and location'. Each mechanism was associated with sub-themes (Fig. 2) relating to both positive and negative spillovers on the family carers.

3.1. Mechanism 1: information

Information alongside the delivery of services was an important influence on the experiences of family carers. Good information about

Table 2
Characteristics of care professionals and family carers participating in the study.

Care professionals	25	Family carers	24
Focus group (n = 4[a])	19	Focus group (n = 3)	20
Interview	6	Interview	4
Stroke	9	Stroke	5
Mental health	9	Mental health	12
Dementia	7	Dementia	7
Doctor/nurse	8	Parent	9
Occupational therapist/physiotherapist	8	Spouse	9
Clinical psychologist	4	Adult child	5
Other (charity, social care, support worker)	5	Other	1

[a] 2 focus groups were conducted with stroke professionals.

the illness, 'how the system worked', and how to care effectively for the patient could help family carers better adapt to their caring role. When care professionals took the time to demonstrate techniques, family carers stated they felt more competent in their role:

> It could be anything … either exercises to improve the swallowing, exercises to improve the movement. It was really good. They left you with something that you could do yourself as well and you felt involved in it. [Cares for husband, post-stroke]

Professionals such as occupational therapists and nurses were often providers of information to the family. Charities and patient support groups offered opportunities for incidental discussions and information-gathering:

> In the cafes they will have things that will help, like the old papers. I went to an Alzheimer one and they had some copies of some old

local papers, which is a good idea. Or play old music and things. Some carers will learn just from example by seeing what is provided in the cafes. [GP with a special interest in dementia]

However, information provision was often lacking. An absence of information could lead carers to feel poorly prepared in their caring role and confused about what services were available and what was to come:

> Understanding what's available I think is the most difficult part of this for a carer and at the various meetings I've been to I've suggested that a flow diagram with contacts on it would benefit everybody who's in our situation. I've been at it now probably about 10 years, I still don't understand the system [Cares for wife with dementia]

Confidentiality in mental health presented a particular problem, limiting information about the patient around admission and discharge. A lack of information could lead carers to feel bewildered and frustrated, leading to relationship difficulties, loss of control, and loneliness:

> Families are left in limbo, really. They're left to work out who is in charge of the care, who to contact. So lots of carers will say, 'We just don't know where to phone to ask.' And then people will say, 'Just phone the switchboard,' so they're phone the switchboard and they don't know what team the person's under. So it's just the lack of information really. And that's not great, is it? [Occupational therapist in mental health]

Information overload also posed a problem for carers. When information was concentrated at the time of diagnosis or discharge, carers could feel overwhelmed and confused:

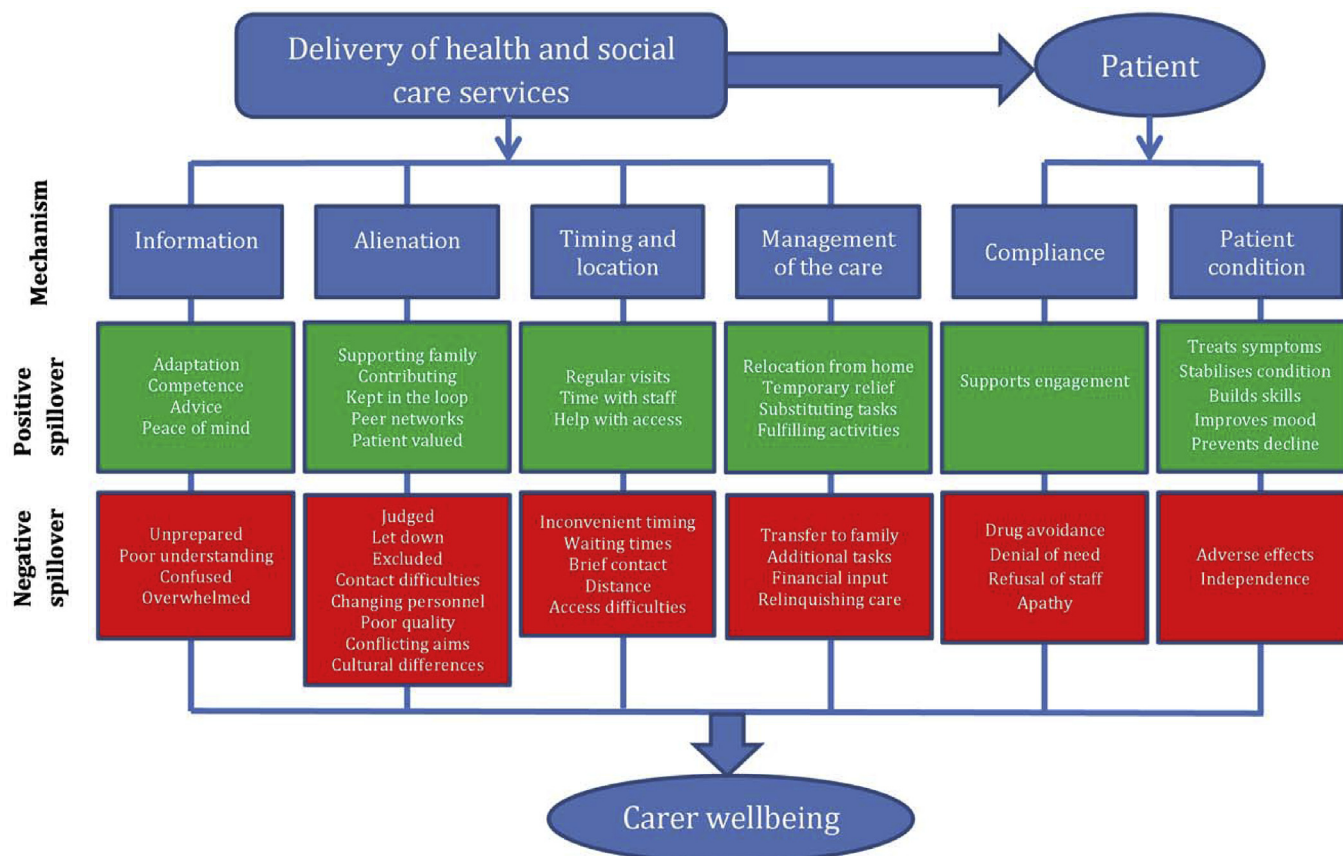> That overwhelming part of it was something I was very conscious

Fig. 2. Mechanisms behind the 'spillover' effects of patient services on carer wellbeing.

about. It's just a way that our service works that it does sometimes feel very overloading. I know I will (and I think we all will) sometimes split it up and do the feedback of the diagnosis and Support Planning separately but one thing I felt was that people are very overwhelmed. [Clinical psychologist in dementia]

Contradictions in the information received by family carers from different care professionals caused problems for family carers. Participants with experience in mental health and stroke care both mentioned the numerous care professionals that the family carer encountered and the difficulties in piecing together the information from each one:

You get one or two individuals who are saying, 'He's doing okay. He's taking his medication' and you get another individual saying, 'We can't tell you that. It's confidential'. Tell me, how can you have this imbalance? [Mother, cares for son with mental health problems].

3.2. Mechanism 2: management of the care

Responsibility for managing patient care was shifted back-and-forth between formal services and family carers and this had both positive and negative effects on carers' lives. Family carers may benefit when asked to take on delivery of an intervention which made the caring process more fulfilling (as for example in delivering cognitive training for people with dementia):

CT[cognitive training] which a carer can give to the person who has got dementia and the evidence so far seems to be that it actually helps the carer much more than the person who has got the dementia. It gives them something positive, it's a positive activity that they can do that sparks conversation and it actually increases the wellbeing of the carer. [GP with special interest in dementia]

However, a more commonly cited route to improving the wellbeing of family carers was through shifting aspects of the management of patient care away from the carer. A number of participants suggested that the admission of a person with severe mental health problems or dementia into a rehabilitation centre, hospital, or residential care could significantly reduce the strain on family carers:

… she had a psychotic attack and they took her in as an emergency and then she went 18 months into a rehabilitation centre in [midlands town] and so we had that time off [yeah] and it's like, if you were to hit your head every morning six times with a hammer and then suddenly there was no hammer and you didn't hit your head [right] you'd then realise how wonderful it is [yeah] … once the trauma of her going in was over [yeah] we realised how different life could be [Mother, cares for daughter with mental health problems]

While the transfer of care management *from* the family to the formal care providers often provided family carers with emotional and physical relief, it could also bring feelings of stigma and guilt for family carers:

It was a two-edged sword really; the feeling of guilt that you can't do what you, as a parent or a carer does, but also that feeling of relief [Mother, talking about son with mental health problems being admitted into hospital]

Participants offered examples where services substituted care that would have been provided by the family, such as social care provision (mentioned mostly in dementia and stroke). This could free up the carer to do other things with their time:

Obviously if the person is able to have respite, even if it's like going to a day hospital, [the carer] can get various things themselves, they can see to their own physical health needs, get to the doctor, go to

their hospital appointments, take more exercise. [GP with special interest in dementia]

In contrast, a rapid and unstructured transfer of responsibility *to* the family often occurred after discharge from a hospital or health facility. The impact of this on family carers was invariably negative:

To suddenly feel that they've got a huge responsibility … although there's formal carers that will probably come in four times a day … this sort of scenario that's still as you say leaves 20 hours a day where the carer is there bearing the burden even if they're not having to do that much - that sense of responsibility is enormous and they literally feel like they can't go out so that's an emotional strain. [Consultant doctor in stroke care]

Post-discharge, family carers may be required to undertake additional duties, for example, acting as care co-ordinators, and liaising with doctors, nurses and other health and care workers. They may also have to contribute to the costs of care:

Everybody is entitled to an assessment by Social Services … we know in reality that some people will not get any funding. That's very difficult. Obviously, it's a very difficult situation and in the Rare Dementia Service, obviously, the carer has to pay for that and we have had some situations where it's been really, really tricky to get somebody to accept that they will need to pay for the care and how much it will be. It's a very tricky place [Occupational therapist in dementia]

3.3. Mechanism 3: patient outcomes

Many services, particularly medication and psychological interventions, were used to treat or stabilise the patient's health condition. This invariably had a spillover impact on those close to the patient. Treatment of patient symptoms was subsequently linked to improvements in carers' emotional health, control, finances, activities, and in some cases, ability to sustain their relationships and caring role:

I was saying to myself, 'Well, this is too much. I can't cope with this. I don't want to be her carer anymore. My life is just being destroyed'. At that point, they put her on [the medication] and overnight, she was a different person … I was at the end of my tether and I was actually thinking of seeing a solicitor. I'll share that with you. I couldn't cope. I was absolutely desperate [Cares for wife with mental health problems]

[when his condition is stabilised] I can sleep in my bed at night knowing … that he's not doing something stupid to himself; that his life is not chaotic … that I'm not going to get that sudden phone call … to say that he's unwell and I've got to drop everything … I can carry on running my business which means I am relieved and I can be emotionally much better off and just a feeling of actually having a good relationship with him. [Mother, cares for son with mental health problems]

Services, such as those delivered by occupational therapists, helped to build up a patient's independence and skills. Family carers valued these improvements because it brought them pleasure, hope for the future, and reduced their caring load:

A lot of it is about that and finding strategies to help people maintain independence; whether that's by equipment, education, doing things differently, reorganising your environment or whatever it is. For a lot of people, really, what they want is to be independent … they're not dependent on the carers to take you appointments, remind you of appointments, remind you take your medication or doing your shopping and if you can find strategies for doing things [Occupational therapist in dementia]

Services such as support groups, psychological care, and

complementary therapies could enhance the mood of the patient. This was seen as something that would 'rub off' on carers, improving their own mood and relationships with the patient:

> If the patient goes and gets aromatherapy or sees an acupuncturist and is then finding improvements with anxiety which is something that acupuncture can treat, then it may just be transferred across. If the carer is spending, say, three days a week with them and they notice the patient is more upbeat, then they themselves naturally take some traits. [GP with special interest in mental health]

Most services to 'treat the patient's condition' were perceived as positive for carers, as an improvement in the patient's condition was typically valued by carers. However, some interventions, notably medication (in mental health and dementia) were associated with side effects that had an adverse effect on the lives of carers. Side effects associated with mental health medication included obesity, mood changes, agitation, and sedation, and these, particularly in combination, resulted in feelings of loss for carers:

> I remember speaking with the father and this person was on a high dose of anti-psychotics and lots of side effects in terms of weight gain and hyper-salivation, lethargy; different things really. And he said that he'd lost his daughter. [Clinical psychologist in mental health]

In some cases, for example, following a stroke (and to a lesser extent in mental health and dementia) services helped the patient to recover their independence. This could cause problems for family carers, who had to re-establish a new balance in their relationship and were anxious about social stigma during the recovery process:

> … we find these issues around anxiety, like, 'Yes, I know they could do it but I'm not happy because there's a busy road'. There's that sort of level of – 'What if people laugh at them because they can't communicate?' – those sorts of anxieties will start to come out through feedback from the client. [Clinical psychologist involved in post-stroke rehabilitation]

3.4. Mechanism 4: alienation

Service delivery could foster feelings of alienation, or conversely inclusion, amongst family carers. Carers felt included when care professionals took the time to discuss things, when they were kept 'in the loop', and when they had the ability to contribute to care decisions:

> If you've got some sort of sense of the medication; why it's being prescribed and what kind of things you might need to look out for. If you've got some sense of why they might behave in a certain way and if you've got some sense of what the Care Plan is and what's going on, I think that has a knock-on effect in terms of that person's quality of life because they feel they're involved, to a degree. … whereas, if you've got a carer who feels that they're not included at all … they're more angry at services and they're more hostile towards staff. [Occupational therapist in mental health]

Services such as charity-run patient support groups enabled carers who accompanied the patients to establish their own peer networks. This brought the carers friendships, support, and information sharing:

> It's more having people who understand because I'd never come across people who'd had a stroke before and people who were experienced. It wasn't until I came to this group, where you meet other people in the same position, that you realise that they don't like to do any exercise with their nearest and dearest [laughter] and they are pretty absolutely horrible to their nearest and dearest. It's that sort of emotional support and understanding really that's so important. [Cares for husband post-stroke]

Another sub-theme related to services being delivered in a way that

valued the patient as an individual. This could come from a care professional making a connection with the patient or care being delivered in a personalised way. While carers may feel undermined if care professionals developed particularly strong bonds with the patient, having a care professional who really understood the patient's unique needs could bring comfort to family carers:

> She [the nurse] was chatty, talking to him in a very understanding way … he's kind of old school in the way that he likes things to be formal you know and, 'Who are you? And why have you come? And whose asked you to come?' and then she'd go through it again and he'd you know and he'd understand … [and] … she would banter with him … and it was brilliant and he loved it you know. [Cares for father, post-stroke]

However, some aspects of service delivery created a sense of alienation amongst carers. For example, the complex web of agencies involved in patient care, ambiguities about what support was available, and lack of continuity of care created negative experiences:

> I was in contact with one person … all of a sudden he rang up and said, 'I was only supposed to have been with you for six weeks and you should have been passed on to somebody else' … I realised that the system itself changes around all the time … they're not dealing with one person and getting bogged down with their problems so they can move around and get somebody else which helps them. But for the person like us it's good to have, to see one face [Cares for husband with dementia]

> They're overwhelmed by all the agencies because they're getting all different messages from different people and they end up feeling, I think, quite impotent in being able to facilitate any change in that person's care. They're so far down the pecking order. [Senior charity worker in mental health]

In mental health, service providers could be reluctant to involve the family either because of the patient's wishes, or because of their interpretation of patient confidentiality. This meant that carers were often excluded and unable to contribute to patient care or have their concerns heard:

> As carers, we're not listened to. They don't ask our opinion. We are the ones that know these people the best and so consequently, the impact on the family … not only the service user but the carers, is massive; just emotionally, financially and every sort of reason [Mother, cares for son with mental health problems]

In some cases, this sense of detachment and frustration, was made worse by the experiences of their loved ones not being properly valued as individuals, or not receiving dignified care, or not being a considered a priority:

> You had this problem, the social services and the NHS would work out together who is paying for what and I actually have been in a meeting where we sat in the middle, NHS were up there, learning disabilities were there, social services and it was like watching Wimbledon [tennis tournament]. No she's not our responsibility, she's not ours … that was horrible to sit there and hear that [Mother, cares for daughter with mental health problems]

3.5. Mechanism 5: compliance with care

Patient compliance or engagement with services was needed in order for the service to benefit the lives of patients and carers. Patients could be supported to engage with services through sensitive, personalised, approaches from staff, or from specific devices, for example slow-release injections for medication:

> He has agreed to go back onto a depot injection, voluntarily, which is what we've always been happier for him doing because it's once

every three weeks and it takes a decision, takes the routine of it. It also keeps him in touch with his care team. [Father, cares for son with mental health problems]

Across many services, patients did not engage or comply effectively and this created difficulties for carers. If the patient wanted to drop out of the care system altogether, care professionals were duty-bound to respect the wishes of patients, even when this meant carers might be left to shoulder the entire caring load:

My son got transferred out of the system completely because he was refusing to take medication … into my care. I managed to keep him pretty stable for 18 months until things became completely mad and then it just went completely chaotic … from my point of view … it was living a nightmare; waiting for the Police to call to tell me if they'd found him. [Mother, cares for son with mental health problems]

When patients did not engage with services, the family had to deal with relapses and extra work in supporting patients. This reduced their free time and could damage their emotional health and relationships:

Very often it caused him to having a relapse. So that does impact on our life. He goes back into hospital. He's maybe very unwell. The whole involvement with him becomes more complex …. supporting him becomes more difficult. He will generally create chaos all around everything in his life. [Father, cares for son with mental health problems]

As noted above, compliance issues in mental health often related to medication, causing the condition to relapse, creating difficulties for carers. However, in dementia and stroke, issues were often encountered with initial engagement with services. For example, patients might refuse to interact with certain staff, have people into their house or attend groups and appointments:

Obviously there's always a stress because often the people who have got dementia don't want some stranger coming into the house. They want the family to do this and often there is this resistance because the family have been doing more and more and more and then the person that has got the dementia will be thinking well why can't they just carry on? [GP with special interest in dementia]

There's a number of lunch clubs and so on but he won't go to anything like that, he won't go to an old people's thing and I think that's all to do with other things that are in his mind about, 'Oh why would I want to do that' … we've tried to do that with him but he just won't have it. [Cares for father post-stroke]

3.6. Mechanism 6: timing and location

Family carers were affected by decisions relating to the timing and location of services for patients. Families valued regular contact with care professionals, who took the time to explain things to them:

My wife would say that she felt suicidal, a lot … that without BFT (behavioural family therapy) she thinks she'd be dead. She thinks she would have committed suicide … BFT was the big saviour for her. One of the reasons for that was because it brought regular contact with the professionals. So even if you weren't discussing something directly relevant to yourself, it was to do with [Son], then you were seeing a professional and you felt slightly comforted [Father, cares for son with mental health problems]

They [occupational therapists] were encouraging [my wife]. The fact that they were coming virtually every day for something made her feel, 'There must be some light at the end of the tunnel or they wouldn't be bothering with me like this'. They were a great group and lovely people. [Husband, cares for wife post stroke]

Family carers also valued it when care professionals were willing to meet patients in informal settings outside of the hospital:

Certainly, from [son's] point of view, they were also able to meet him in social situations rather than always wheel him into a clinic, which he never really liked. They would meet him over a cup of coffee somewhere, which he's always more responsive to. So it worked better for him as well that sort of setting. [Father, cares for son with mental health problems]

In contrast, difficulties arose when patient care was delivered 'out-of-area' which increasingly happened with mental health. This made travel time-consuming and expensive and resulted in a loss of control and support for carers, as well as ultimately damaging relationships:

Yeah, when my son went through a psychotic incident and there were no beds in any local area, so he was shipped up to [Northern town]. There was just no way that any of us could do that. Again, as I said before, I work myself. There was no way I could take a day to get in the car, drive to [Northern town], visit him for an hour if I'm lucky and then drive back again. I looked at the finance of staying overnight and, of course, somewhere like [Northern town], there was no way [Mother, cares for son with mental health problems]

So financially, socially, employment – all of these things can be if not dented, totally destroyed by an admission to hospital. The average length of stay in our Local Psychiatric Unit is three months. That's a long time out of somebody's employment. That's a long time of the family environment. The extended family slips off the end. Friendships break … that's extremely destructive to the family dynamic [Senior charity worker in mental health]

Furthermore, certain factors to do with the way services were timed, negatively affected the lives of family carers. Appointments with health care professionals during working hours could be difficult to attend. With social care, time slots were often not guaranteed or did not fit with patient routines creating organisational challenges for family carers. Missed appointments and waiting times were also huge source of frustration to carers. Often these resulted in family carers taking matters into their own hands at great personal and financial expense:

[Social care] are being late all the time, or they're not doing what they want, or another common thing is their scheduled to stay for half an hour but they stay for ten minutes. Sometimes, family carers just say, 'I give up with this' and then they'll give up their jobs. [Occupational therapist in dementia]

We often discharge people knowing that they've got three steps in and they can't get in and out but they're on a waiting list to have a ramp that could be two years so families will go ahead and sort it themselves. [Physiotherapist in stroke]

Fig. 2 summarises the six mechanisms, as well as the positive and negative sub-themes associated with each of the mechanisms.

4. Discussion

To date, there has been little conceptualisation of the mechanisms by which patients' health and social care services affect family carers' wellbeing. Such an understanding is important; both for evaluating the effectiveness and cost-effectiveness of current health and social interventions, and potentially in designing services for the future that can maintain the wellbeing of family carers as well as patients. This qualitative study identified six mechanisms by which patient services generate 'family carer spillovers'.

The finding that 'patient outcomes' was a key mechanism is consistent with earlier theoretical and quantitative work (Bobinac et al., 2010, 2011), indicating that spillovers occur because carers *care about* and *care for* patients. The patient outcomes mechanism highlights the emotional and relational benefits family carers can derive from services

that improve the patient's health and independence, in addition to the practical benefit of having to provide less care. Three other mechanisms (management, compliance, and timing/location), and the associated sub-mechanisms, highlight the practical ways in which services affect the scale and scope of family care. This complements previous studies which have identified, for example, some of the practical challenges facing carers, attitudes to handing over management of the care (Nolan et al., 2004; Van Exel et al., 2008) and issues in supporting patients' compliance (Aston et al., 2017; El-Saifi et al., 2018). The present study demonstrates that the service delivery has a nuanced effect on carers' lives. For example, increasing family carer input may have a positive impact on the carer's wellbeing if, for example, the new activity is fulfilling or enhances the carer-patient relationship.

Two mechanisms (information and alienation) highlight less obvious channels by which patient services can affect family carers. These interlinked mechanisms, emphasised that patient services could be a force for good in the carer's life with timely, well-judged information and support providing an 'umbrella' over the family. This could be effective in reducing uncertainty, social isolation and feelings of helplessness and ultimately help improve relationships and provide hope for the future. Conversely, service delivery left family carers in despair when care professionals excluded the family and there was a lack of signposting and organisational complexity, coupled with high staff turnover and fiscal austerity. These findings complement a rich literature on, for example, family carers' information and support needs (Pinquart and Sorensen, 2003b; Wackerbarth and Johnson, 2002) and feelings of social alienation (Lefley, 1996).

It has been widely argued that researchers must take a broad view of costs and benefits when evaluating interventions, within healthcare, across public health and in social care (Drummond et al., 2008; Weatherly et al., 2009; Sanders et al., 2016; Byford and Raftery, 1998). This study suggests that a broad perspective, encompassing impacts on the family, is particularly important when evaluating changes to the organisation and delivery of services (Meacock, 2019) and disinvestment activity. There is real potential for health and wellbeing harms to carers, from many organisational changes. Examples highlighted through this study included decisions to: relocate patient care, close day centres and increase care professionals' case-loads. Many of these decisions are less visible (and less well-evaluated) than decisions around the adoption of new technologies, yet, if anything, appear to have broader and more significant welfare consequences. Furthermore, some interventions that are positive for the patient may be negative for family carers. For example, some elements of rehabilitation clearly put great strain of family carers (at least in the short term). Again it is important to capture these effects to estimate the net effects of intervention on costs and outcomes of all in society, as well to help understand how to deliver services to enhance wellbeing of all society.

This study deliberately sampled a broad array of participants, across health and social care and across the three conditions. The breadth of the sample and study topic was both a limitation and strength of the study. The breadth meant that the commonalities across the conditions, in terms of how services affected family carers, could be noted. This resulted in a more generalised understanding of the mechanisms for carer spillovers. This could be helpful as a starting point for studying spillovers in other contexts too. The drawback on the broad sampling strategy is that there was not a detailed focus on family carer spillovers in relation to a specific service, condition, or group of family carers. The focus on the underlying mechanisms (and sub-themes) also inevitably masks some of the heterogeneity in the data. For example, the study has not focused on when certain aspects of service delivery were most likely to challenge carers and which carers were most likely to be challenged by this.

The use of prompts for the focus groups is likely to have influenced the findings. Initial contact with carers (through the lay panel) had suggested that it was difficult to ask people directly about the different ways in which services for patients affect the wellbeing of carers. The use of the prompts ensured the discussions in the focus groups and interviews covered specific aspects of service provision (such as medication and transfers between care settings) and specific impacts on carers' lives (such as emotional health and finances). In this way the focus groups' discussions could focus on specific challenges and benefits, rather than general discussion. The intention of the study was to derive a common set of mechanisms. However, there was clear heterogeneity across the sample in terms of what was important to family carers in different contexts. For example, a major 'information' concern in stroke related to information overload when the patient entered hospital. On the other hand, in dementia the major 'information' worry was the lack of information available between diagnosis and residential care.

The sampling for the study was pragmatic, in the sense that focus groups comprised members of a single multi-disciplinary team or members of a local charity group. This had the added benefit of participants feeling comfortable with one another. However this may have promoted an element of 'groupthink'. Steps were taken to mitigate this through also sampling individuals from outside of these organisations for each condition.

The six mechanisms could assist health economists, and indeed the wider health services research community, in hypothesising the potential outcomes of a service change. The mechanisms would enable researchers to enrich the underlying logic models behind the service, by identifying a wider set of potential (intended and unintended) outcomes. Specifically the IMPACT mechanisms (and accompanying sub-mechanisms) would enable health economists to 'screen' for potential carer spillovers; this could inform decisions about whether to include carer outcomes in economic evaluations.

There are several research opportunities worth noting. Firstly, the plausibility of the six mechanisms could be studied in other contexts where spillovers are likely, such as cancer (Prosser et al., 2015; Nijboer et al., 1999), services for children (Brouwer et al., 2009), or those needing end-of life care (Christakis and Iwashyna, 2003; Canaway et al., 2017). Secondly, the mechanisms could aid the formulation of policy and the design of services where the objective in optimising the wellbeing of both patient and family carer(s). Finally, the IMPACT mnemonic could provide the basis for a tool for health and social care education and training as a means of raising awareness of spillover effects in practitioners.

In conclusion, this qualitative study, with a diverse sample of family carers and care professionals, has identified six underlying mechanisms by which patient services spillover to affect the wellbeing of family carers. The mechanisms can be summarised by the mnemonic IMPACT. Further testing could potentially explore the generalisability of the IMPACT mechanisms across other conditions. The systematic consideration of these mechanisms in designing and evaluating services, especially service delivery, could contribute to an improved evidence base for delivering services to improve the wellbeing of carers as well as patients.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2019.112382.

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