

HOW ARE PATIENTS WITH RARE DISEASES AND THEIR CARERS IMPACTED BY THE WAY THEIR CARE IS COORDINATED IN THE UK?

An exploratory qualitative interview study

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Background

UK policy frameworks highlight the importance of care coordination for rare conditions. Yet, there is a lack of evidence exploring if and how patients and carers are impacted by the way in which their care is coordinated. We aimed to explore how care coordination (or lack of) impacts on patients and carers.

Method

We conducted semi-structured interviews with 15 UK-based patients and carers/parents with lived experience of a range of rare and undiagnosed conditions. Transcript data were grouped into themes and sub-themes.

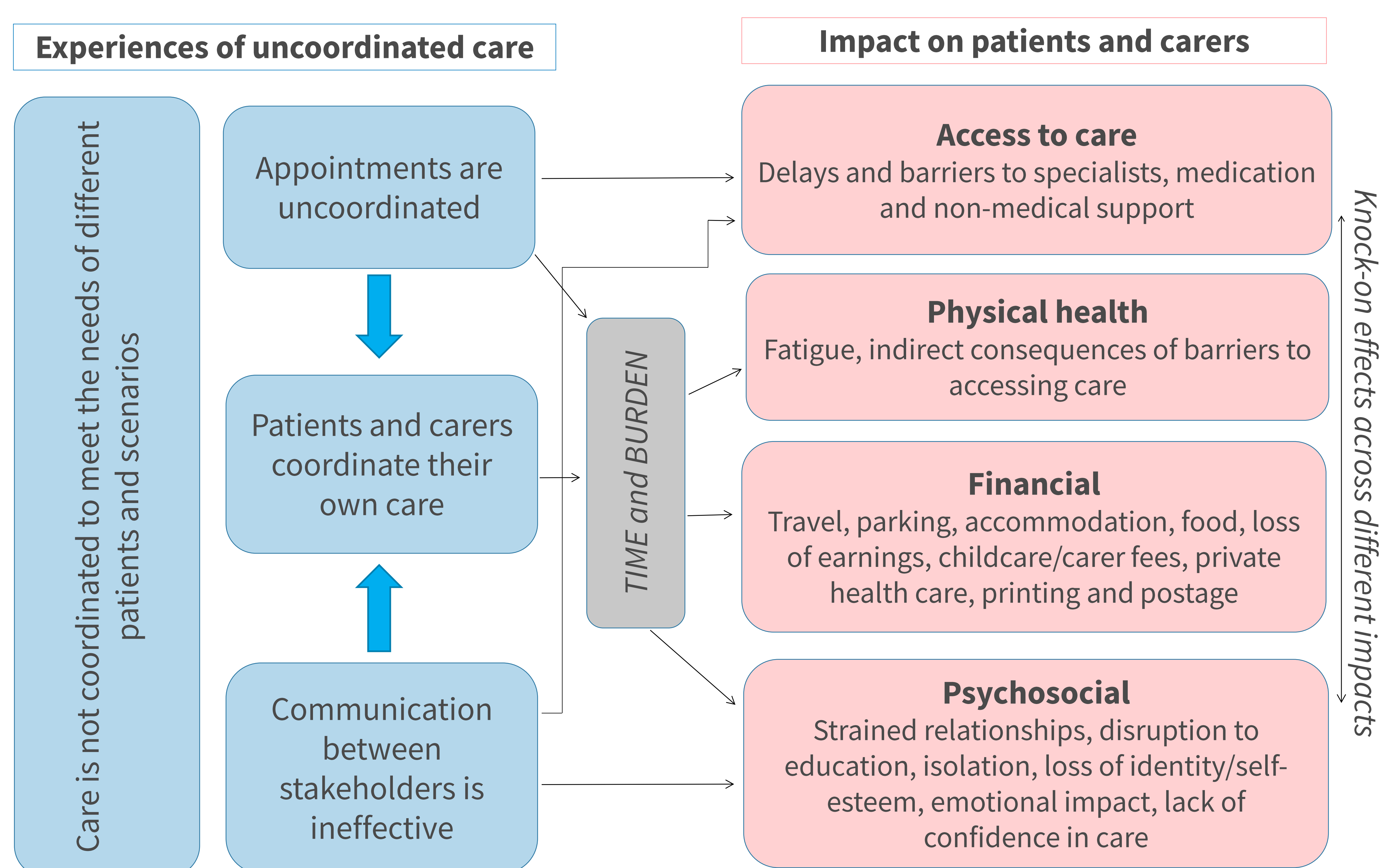
Findings

- Participants reported that their care was uncoordinated in four key ways (see 'experiences of uncoordinated care' in figure 1).
- Patients and carers were negatively impacted in terms of their finances, psychosocial and physical wellbeing, and access to care (see figure 1).
- Many of the impacts were attributed to the time and burden felt by the individual(s) who attended appointments and took on the key role of coordinating care.

Negative impacts could be reduced by:

1. Having the support of a professional to coordinate care
2. Changing the approach of clinics and appointments (eg where they take place, which professionals/services are available and how they are scheduled)
3. Improving communication between professionals, services and patients (eg by using technology)

Figure 1: Patient and carer experiences of uncoordinated care and their impact



'I think anybody that's in a position like I am should have an appointed care coordinator, an appointed person to go to that pulls everything together, that looks at [the] whole person.' [patient and carer, diagnosed rare condition]

'...there are instances where it has been coordinated well by being able to condense all my appointments into one day, which is obviously much kinder on the bank balance... Obviously, it's got a financial cost, but there's a physical cost there, you know, having to go to extra appointments when I needn't have to.' [patient, diagnosed rare condition]

'I would like there to be one central website where I could log in... I could see when he's due to see them next, I could message Consultants... and I could book appointments; maybe I could see his test results and stuff too... to actually access these digitally and online would be fantastic.' [carer, undiagnosed rare condition]

Conclusions

Our findings suggest that uncoordinated care has a negative impact on patients, and their families, in many different ways. Models of care coordination which lessen the time and burden placed on families may be particularly beneficial in reducing these impacts. Findings should influence future service developments (and the evaluation of such developments). In the first instance, findings will inform the [COordiNated Care of Rare Diseases \(CONCORD\) Study](#).