Decision-making about appointment type in complex primary care: What matters to patients?

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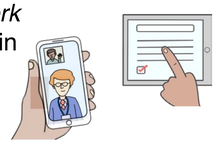
Key Messages:

1. What really matters for primary care patients is achieving a coherent experience of health and care.

2. Patient narratives highlight the *work* patients do to achieve coherence in a complex, fragmented and increasingly digitalised system.



3. We challenge the notion of 'the complex patient': complexity can be produced by the systems patients must navigate – it is not just an inherent quality within patients.

ModCons Study: The Patient Perspective

The ModCons study explores decision-making about appointment type in primary care (the Mode of Consultation):

- WHAT kind of appointment (remote or in-person)
- WHEN it takes place (urgent or routine)
- WHO it is with (GP or another clinical practitioner)

The wider ethnographic study explored the people, technologies, processes and practices involved in decisions about care in three case study sites in England.

This focusses on **the patient perspective,** asking:

What matters to patients with complex care needs when it comes to the type of GP care they receive?

Theoretical Framework

We focus on the patient perspective on decision-making, foregrounding relationships and tensions between:

1) Complex patients

2) Complex systems of care

WHAT MATTERS TO PEOPLE (Greenhalgh et al, 2013)

Decentring technologies and placing *what matters to people* at the centre of analysis

INFRASTRUCTURES OF CARE (Langstrup, 2013)

Attention to the arrangements of people, spaces and objects that enable the negotiation of chronic illness.

BURDEN OF TREATMENT THEORY (May et al, 2014)

Focus on the work that patients and their networks do to understand variation in healthcare use.

Methods: Narrative interviews & patient involvement

DATA COLLECTION

- Narrative interviews with 18 patients with complex care needs (Salisbury et al 2021) from 3 ethnographic case study sites
- Review of medical records of clinical encounters within last 24 months

DATA SYNTHESIS

- 18 structured patient narratives based on interviews, medical records, and wider ethnographic observations from main study

DATA ANALYSIS

- Preliminary thematic analysis by the research team informed by our theoretical framework
- Collaborative analysis with patient representatives with complex care needs over a 1-day workshop plus a team writing retreat.

Findings – What Matters?

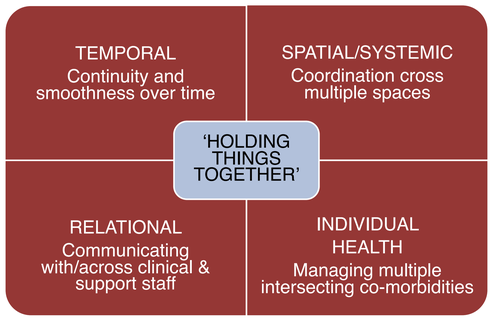
Preferences about mode of consultation varies between individuals and changes per *situation* and over *time*. However, what really matters for patients, is **achieving a coherent experience of health and care in a complex and fragmented system.**

Patients are "conductors of a care orchestra" (PPI rep)

With increasing complexity in primary care with new technologies, multi-disciplinary teams and a fragmented system, the work to coordinate care is being shifted towards the patient.

Narratives highlight the **work people do to 'HOLD THINGS TOGETHER',** to achieve coherence along different dimensions: temporal, spatial/systemic, relational, and individual health.

ACHIEVING A COHERENT EXPERIENCE OF CARE



Patient work: key themes & examples

TEMPORAL: Moving things along
Patients manage waits, gaps or ruptures in care with practical and emotional labour: for example, LINDA has work-arounds to creatively navigate getting stuck in the call queue, KATHERINE communicates urgency by focusing on aspects of her mental health that she knows make her 'high risk' on the phone to support staff.

SPATIAL: Connecting multiple spaces of care
FAIZA recently moved cities "for love" but stayed at her surgery because they know and support her complex care needs. She utilizes remote care and coordinates across different providers. She uses digital technology (e.g. SMS and online consultations) as a 'log' to keep track of information on her health and care.

RELATIONAL: Keeping everyone in the loop
KEVIN's wife keeps in touch with the GP by letter (dropping it in in-person with the receptionist). She feels it important to maintain dialogue with the GP about Kevin's health, changing events – especially as his care spans primary, secondary services, as well as various ambulance/emergency and 111 encounters.

INDIVIDUAL: Managing comorbidities
TINA prefers longer appointments to discuss all her physical/mental health needs in one appointment with enough time to express these needs and feel listened to. Current IT systems don't allow for extended appointments, so she relies on the discretion of the GP.

Discussion

KEY CONTRIBUTIONS

- Our findings make visible the work patients put into creating and maintaining what matters to them when it comes to appointment type in primary care – namely, a **coherent experience of health and care.** This builds on research by Ladds & Greenhalgh (2023) on continuity of care in a digital age.
- This raises concerns around widening (digital) inequalities, as disadvantaged patients will often be less able to carry out this work of 'holding things together'
- Collaborative analysis with patients with complex care needs pushed us to see how increasing complexity in the healthcare system is **producing additional complexity** in patients
- We therefore **challenge the notion of 'the complex patient',** arguing that complexity can be produced by the systems patients must navigate – not just an inherent quality within patients.

LIMITATIONS

Our selection of patients was based on a clinical view of complexity (Salisbury et al, 2023). Although this took social, behavioural and psychological factors into account, we could have brought the patient-perspective in earlier in by co-producing our definition of complexity with patients. Our case study sites did not include 'deep end' practices, so disadvantaged patients were underrepresented in our sample.

Implications for clinical practice:

1. Triage decision-making should prioritise achieving a coherent experience of care, over any single appointment type (e.g. 'in-person' or 'urgent')
2. New technologies and expanded practice teams in Modern General Practice (DHSE 2023) mean patients must actively coordinate their own care. This can exacerbate existing patient complexity and widen inequalities.
3. Rather than labelling patients, we need to address our systems. Some interventions aimed at 'complex patients' could be reframed to address complex (digital) systems in primary care.

References:

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