Reflections on an international workshop on 'missingness' in health care,

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Abstract

This special report from a workshop at NAPCRG 2019 about 'missingness' in health care discusses current research, sensitising concepts and reflections on what workshop participants reported as important factors. Recent research about patterns of missed appointments at the patient level in Scotland has highlighted for the first time the importance of this topic for mortality outcomes.

Many of the person, family medicine and hospital care factors discussed in the workshop are common across the globe, but some are distinct.

We were particularly struck by the importance given to transitions in care and the role of the 'cold' or 'warm' hand off between care providers. How much do patients' themselves feel 'touched' by the system at these important care moments?

These opportunities for discussion provide useful reflection for clinicians and researchers and we hope will help shape the future research and clinical practice development agenda on achieving health equity.

Introduction

Twelve primary care clinicians, researchers, and experts by experience from Canada, the USA and the UK took part in a workshop about the role of health care systems in engagement in care at NAPCRG 2019, Toronto, Canada.

The workshop facilitators have undertaken research on patterns of missed health care appointments at the patient level in Scotland UK. They shared findings from this research, described sensitising concepts and asked workshop participants to reflect on the influences in their own health care systems that impact on patients' abilities to engage in health care.

Scottish research about missed appointments at the patient level

Research on this topic utilised routine data from a sixth of the Scottish populations general practice (GP) records, and for the first-time characterised patterns of missed appointments at the patient level. It was conducted in a universal access, free at the point of care health care system where almost all the population are registered with one family doctor (GP) with a comprehensive health record from birth to death.

It found that patients with high rates of missed appointments (on average more than 2 per year) were aged between 16 and 30 or over 90 years old; and were more likely to be socio-economically deprived. Patients were most likely to have high rates of missed appointments if they lived in an urban setting, and additionally if their GP served a predominantly affluent population. An appointment delay of 2-3 days was an important factor (1).

Patients with more long-term conditions had increased risk of missing GP appointments (controlling for number of appointments made) and were at much greater risk of all-

cause mortality, the risk increasing with the number of missed appointments (independent of morbidities). The starkest finding was that patients with long-term mental-health conditions missing >2 appointments per year had >8x risk of all-cause mortality compared with those similar diagnoses who missed no appointments (2).

Sensitising concepts

Workshop participants were encouraged to consider low engagement in care as 'missingness'; who is missing from our services and why? They were also encouraged to consider examples where health services enact explicit inclusion.

Candidacy theory was discussed as a useful way of thinking about 'missingness'; it encourages consideration of how the patient views their legitimacy of being eligible for services, how they might navigate services, the role services have in this, the local context for how the service is delivered and the impact this may have on continued use by the patient (3). Participants were encouraged to consider 'the work of being a person' which takes account of the structural, social and personal determinants of health that an individual patient may experience and the role that plays in capacity to engage in health care. Finally, the concept of 'stickiness' of services- how much a service is able to 'stick' to a patient irrespective of the patient's actions- was explained as a way to think about service configuration; does it have a role in the patients' journey through health care?

Participants were asked to reflect on their professional or personal experience and to note person-based, family medicine-based and hospital care-based factors that might promote or reduce engagement in care using visual cues, pens and sticky notes. They were asked to endorse factors they agreed with; and then in groups, organise these into themes. The findings were then discussed.

The factors that promoted high engagement in care were often the opposite of those that led to low engagement in care.

Person factors

Participants considered provision of the right information and in an understandable language were important along with level of health literacy. Accessibility of the service, including appropriate appointment times, and how well a person understood the system were also mentioned. Overall health status and mental health were considered

important. The role of disability and experiencing addictions were mentioned along with agency - the ability a person has to understand, engage and invest in their own health. Family support was felt to be important: a person or friend accompanying the patient had a positive role, and conversely with family stressors, isolation or loneliness played a negative role.

Many participants reported that if a person did not feel listened to, if there were cultural insensitivities or lack of understanding, if a person had internalised feelings of weight bias or stigma or had had previous negative experiences with health care they would be more likely to miss appointments.

The experience of poverty, the cost of care and lack of transport were considered important. A minority of participants felt that some patients had a fear of registering for services due to concerns about deportation or the police.

Family medicine factors

Participants reported that providing appointments right away in an office that was geographically proximal were key factors in increasing engagement in care. They also felt that short wait times in the office, reception staff and physicians that were open and friendly, with good follow up (e.g. test results) were important too. A range of positive clinician characteristics were discussed as well as how well office hours and scheduling met the patient's needs, whether appointment reminders were made, language adaptions, and whether the patient's chosen provider was available. How easily the service was to navigate, whether patients were discharged and if patients needed identification papers to use the service were also discussed.

Hospital care factors

How the system could be navigated and accessed along with communication were reported in a similar way to family medicine factors. However, the reputation of the provider, patients being 'touched' by the system at transitions of care and how much care coordination and hand-overs of care back to family medicine were discussed, alongside the role that being an 'unattached' patient meant to low engagement and the role of communication in that.

Reflections

Many of the person, family medicine and hospital care factors described above are common to all health care systems globally. Some are distinct to fee for service or health insurance related systems such as the importance of cost. The role that marginalised patients such as those with cultural or languages different from the prevailing was more amplified in this workshop than is found in the current literature.

We were particularly struck by the importance given to transitions in care and the role of the 'cold' or 'warm' hand off between care providers. In some regards this aspect of care seems so embedded in systems like the NHS that we do not pay much attention to it. However how much do patients' themselves feel 'touched' by the system at these important care moments?

We found convening this workshop with participants from a range of health care systems and experiences was valuable; there was much common ground and some important distinctions that have given us a shift in perspective as we continue our work. We encourage colleagues in clinical practice, teaching and research to consider 'missingness' in health care as part of the future agenda for achieving health equity in our health care systems.

Conflict of interest

None declared.

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