

Health professionals, patients and chronic illness policy: a qualitative study

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Abstract

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Background and objective This study investigates health professionals' reactions to patients' perceptions of health issues – a little-researched topic vital to the reform of the care of chronic illness.

Methods Focus groups were undertaken with doctors, nurses, allied health staff and pharmacists ($n = 88$) in two Australian urban regions. The focus groups explored responses to patient experiences of chronic illness (COPD, Diabetes, CHF) obtained in an earlier qualitative study. Content analysis was undertaken of the transcripts assisted by NVivo7 software.

Results Health professionals and patients agreed on general themes: that competing demands in self-management, financial pressure and co-morbidity were problems for people with chronic illness. However where patients and carers focused on their personal challenges, health professionals often saw the patient experience as a series of failures relating to compliance or service fragmentation. Some saw this as a result of individual shortcomings. Most identified structural and attitudinal issues. All saw the prime solution as additional resources for their own activities. Fee for service providers (mainly doctors) sought increased remuneration; salaried professionals (mainly nurses and allied health professionals) sought to increase capacity within their professional group.

Conclusions Professionals focus on their own resources and the behaviour of other professionals to improve management of chronic illness. They did not factor information from patient experience into their views about systems improvement. This inability to identify solutions beyond their professional sphere highlights the limitations of an over-reliance on the perspectives of health professionals. The views of patients and carers must find a stronger voice in health policy.

Background

The question we ask in this paper is whether there are differences in the ways health professionals and people with serious and continuing illness see the problems and solutions of long-term illness. If there are, understanding these might contribute to finding more effective policy and system changes and produce better outcomes, more efficiently. While evidence exists about health professionals' views of problems faced by patients with chronic illness,¹ previous studies have not used the expressed views of patients as their starting point.

Health professionals and people's perspectives have been a central element of the chronic care models that emerged in the 1990s. The effectiveness of the Wagner Chronic Care Model (CCM)² is determined both by the perspectives patients have on their capacity to self-manage and by the perspectives health care providers have of patient-centred care. However, most discussion of the model moves quickly from affirming these perspectives to models of organization and delivery of care.

In Australia, chronic illness/chronic disease, both terms used for long-term conditions, has been the subject of policymaking at both the national and state levels since the mid-1980s and has reflected many of the international dilemmas. Responsibility for health is shared between the Commonwealth government and the individual states and territories. The Commonwealth is the source of most funding, reimbursing expenses on a fee-for-service basis through the Medical Benefits Schedule (MBS). The national Pharmaceutical Benefits Scheme (PBS) provides subsidies for most prescription medicines, with greater subsidies for older or poorer Australians. States and territories have principal responsibility for public hospitals and community health services.

National policy initiatives have included the National Chronic Disease Strategy and National Service Improvement Frameworks for particular conditions.^{3,4} These policies have consistently identified several systemic issues: the need for service integration, problems of poor commu-

nication and access to information and the importance of patient centred approaches and support for self-management. These issues also appear in state and regional strategies. The approach has been central and driven by medical and managerial priorities, rather than the identified and expressed needs of patients.

The impact of these strategies in reform of the management of long-term conditions has been disappointing. Reform dissipates in the complicated chain from federal decision-making through state and regional health administration and implementation. A recent survey of the experience of general practice examined a series of promising experiments in better co-ordinated care and the increased use of incentives by creating new Medicare fee-for-service items such as chronic disease management plans.⁵ There were few signs that these changes were being generalized across general practice. The study noted that substantial change would require both a clear national strategy for primary care and the development of a 'common clinical governance culture within general practice'.

In this paper, we report the findings of a series of focus groups and interviews which were conducted to gain insight into health professionals' perspectives concerning care of people with chronic illness in hospital and primary and community care settings in two Australian urban areas. Participants were presented with findings from an earlier study of patient and carer perceptions of chronic illness and the possibilities of improved care.⁶ We obtained their reactions to the results of the detailed exploration of the perspectives of patients and carers living with serious and continuing illnesses.

Methods

A qualitative study of the experiences of people with common chronic illnesses and their carers was undertaken as part of the Serious and Continuing Illness Policy and Practice Study.⁶ Fifty-four patients and 14 carers recruited from health services and consumer organisations each took part in a semi-structured in-depth interview

lasting 45–90 min. Content analysis using a coding framework iteratively developed by the research team indicated that data saturation had been achieved. A more detailed account of the methodology used in the patient and carer study is reported elsewhere.⁶ Analysis revealed that people with chronic illness and their carers said they faced significant difficulty managing their chronic illness in three areas:

1. economic hardship;
2. the complexity associated with managing co-morbid conditions;
3. multiple competing demands inherent in balancing illness and its management with the desire to lead a normal life.^{6,9,10}

The current study used 10 focus groups and seven interviews ($n = 88$) in two urban settings to explore the health professionals' perspectives on these issues. Participants were recruited through local 'champions' of the project and purposive sampling was used to maximize vari-

ation of the sample. Two groups of general practitioners (GPs) and primary health care staff, one group of community-based and one of hospital-based nursing and allied health professionals (physiotherapists, occupational therapists, psychologists and social workers) were recruited from each area. Two hospital specialists were interviewed separately using the focus group discussion triggers as they were unable to meet designated focus group schedules. Two of the focus groups and five interviews were conducted with hospital and community pharmacists.

Focus groups of health professionals were held at work locations and at times consistent with working patterns. Members of each group were known to each other as work or as professional colleagues. Selection on this basis, rather than on a random or mixed basis follows Kitzinger's⁷ view of the benefit of using groups that 'naturally discuss these sorts of issues with each other'.

Table 1 Patient concerns and health professional responses

Patient concerns	Health professional responses
Individual level	
Economic hardship Seen in immediate terms problems of daily life: budgeting, paying for transport and financial barriers to access	Poor priority setting Cost barriers a proxy for moral failure (a few) Shaped by social structures: broader welfare problem (majority)
Managing co-morbid conditions Lack of control, competing messages from professionals	Compliance failures
Competing demands Personal limitations imposed by living with illness and attempting to maintain a 'normal' life	Inability or unwillingness of patients to focus on management of conditions Low health literacy resulting in poor motivation and poor ability to navigate health system
Service level	
Economic hardship Fragmentation incurs monetary costs in unnecessary travel expenses, medication changes	Cost shifting Problem of poor infrastructure, cross sectoral issues, often outside health system
Managing co-morbid conditions Fragmentation incurs time costs – waiting for multiple appointments	Communication gaps between professionals and professional organisations Lack of time causing fragmentation
No streamlining or harmonisation of services across conditions	Poor communication between different professional groups Weak electronic information storage and exchange
Competing demands Obstacles in navigating health system	Service fragmentation
Treatment by multiple, poorly communicating individual health professionals	Lack of accountability between service groups Remuneration systems blocking co-ordination of care

Each focus group of health professionals was moderated by a facilitator. Another researcher scribed and summarized discussion and the conclusions reached.

At the beginning of the session the facilitator gave a verbal overview of the earlier study and its results, concluding with an overview of the intention of the group or interview: to obtain their views about the issues and solutions identified by patients; their own ideas about what problems they faced in managing chronic illness and their suggestions for system improvement. Information was provided on the day of the contact to enable participants to respond to the findings afresh and not to arrive with rehearsed ideas.

Proceedings were recorded, transcribed verbatim and placed on a computerized qualitative data analysis program, QSR NVivo7. The data were analysed using content analysis to identify individual concepts⁸ of health professionals' perspectives. Using the NVivo 7 matrix function, the inter-relationships between concepts were examined.

Results

Content analysis identified two principal themes in health professionals' perspectives, namely, patient compliance and service fragmentation. We used the term 'compliance' as it was used by a number of the health professional participants and implied by others who did not use it expressly. Although related constructs such as 'adherence' are frequently used in the literature, we use compliance in this paper to label the view that patients' actions are frequently at variance from those considered normative or optimal by their health professionals.

'Service fragmentation' was also a term used by health professional participants meaning that many components of the Australian health system operate independently with limited communication or commonality of goals.

Four concepts: financial challenges, seeking help inappropriately, poor health literacy and co-morbidity were linked to the concept of compliance. Three others: inadequate access,

lack of continuity and dysfunctional health care culture were linked to the concept of fragmentation. One concept: health professional attitudes and behaviour, was linked to both the health professionals' perspectives on compliance and fragmentation.

Health professionals' suggestions for improvement addressed inadequate access, lack of resources, fragmentation of services, dysfunctional health care culture, other health professionals' attitudes and behaviours and patients' lack of compliance.

Overall, health professionals held many perspectives in common with people living with serious and continuing illness about the challenges associated with managing chronic illness (Table 1). However, despite these commonalities, the language used by different professional groups varied and there were contrasts between the professionals' and patients' perspectives which are explored below.

Compliance

People with chronic illness struggle to juggle the competing demands of their lives, including but not limited to the challenge of managing their health.⁶ Patients had described the problems they faced in managing their lives, dealing with the costs of illness, the personal limitations imposed by ill health and the obstacles faced in negotiating the system.^{9,10} In contrast, health professionals often used the term 'compliance' as though patients had a full control over their management, saying, for example:

Compliance is a big issue and they have to get their head around that idea that it'll be OK if they do what they're supposed to do, but they're not used to doing that. (GP)

There was widespread agreement on this proposition amongst the health professionals although this was expressed in a variety of ways.

Each focus group raised the actual cost of compliance – how patients could give adequate priority to health care in the face of other demands on family budgets. They saw personal priority setting as a key compliance factor.

A small minority of professionals saw lack of compliance as a moral issue stemming from patients' failure to make good choices. For example,

I walked into a house in a housing commission area, and they had this enormous big TV, wasn't flat screen then, and I thought, I don't even have a TV like that, and this is in one of the houses, well that's where their health priority is, they've got this beautiful big TV in the lounge room, so the kids are living in squalor with no shoes on, and just filthy, and food all over the place, and that's their priority, the big TV. (GP)

More commonly, professionals took a structural perspective on compliance. Nurses and allied health staff saw patients making choices between rival necessities: tradeoffs between paying essential bills, buying good quality food and paying for medicines. They and hospital specialists recognized that these difficulties were made worse by the perceived higher cost of purchasing recommended 'healthy' and 'special' food.

Elements outside the control of individuals were seen as affecting compliance, starting with the burden of expenditure and limited resources of their patients.

I think obviously they don't have money to buy drugs, that's the problem. But I mean a lot of them have become non-compliant with their medications. (Hospital Specialist)

All groups discussed the costs of medications. One group of GPs in the study argued strongly that the subsidies provided under the PBS and linked safety net arrangements that limit co-payments for people with long-term conditions, provide such good value on an international comparison that no one could reasonably complain about the expense of prescribed medications. They were in the minority: the overwhelming view of health professionals was that medication and other treatment costs are prohibitive. For instance, some essential treatments such as home oxygen are not subsidized fully under the PBS. Health professionals widely believed these costs lead to patients rationing their treatments, selectively filling prescriptions based on how they feel, storing partly used

courses of medication for later use and, at times, sharing medications with relatives and friends.

Cost was also seen as a factor in patients' abilities to effect lifestyle changes. Most groups identified the prohibitive costs of individually focused preventive health, such as gym membership and weight loss programs. Patients focused more on physical limitations and logistical barriers, such as transport and parking.

Health professionals linked compliance to health literacy – the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.¹¹ They saw formal learning as crucial to the patient's ability to make appropriate management decisions. One specialist said:

If you educate patients about their condition, about their medications, they have a greater familiarity and that familiarity breeds confidence, that confidence means that they're comfortable with their condition. It means they'll self-manage. No education, no understanding, no self-management. Or if there is self-management, it is a disaster. (Hospital Specialist)

As part of improving health literacy, nurses, allied health staff and GPs described one of their roles in terms of motivation and behavioural change. For example:

I think each time they come in if you don't overwhelm them initially I could get them in here and have a bit of a chat to them, and sort of a little bit at a time they actually seem to accept it a little bit better and they are a little bit more compliant. (Practice Nurse)

They focused on getting the patient to recognize the seriousness of their condition, manage risk factors and change behaviour. GPs pointed out that patients were often not effective in navigating care. If they were, it would allow more efficient use to be made of health resources by allowing doctors to spend more time treating illness and less on facilitating connections for the patient. One focus group discussed the importance of recognizing peoples' different learning styles and abilities and their varying needs for knowledge at specific times as factors in successful self-management. They wanted more

support to act as teachers and mentors in patient self-management.

All groups recognized that patients often received inconsistent and contradictory advice from the health professionals involved in care. GPs described their frustration managing co-morbidity when other professionals give patients alternative information and strategies. Nurses and allied health professionals identified the confusion felt by people with multiple conditions when they received conflicting or different advice from professionals.

If you're saying this, and they're saying that, either one of you is wrong, or both of you are wrong. (Nurses/Allied Health)

All groups spoke of the confusion and additional costs faced by people with multiple medications, prescribed often without consultation between treating practitioners: another point of agreement with the patient interviews. Pharmacists in particular raised the cost problem for people in having scripts filled and then replaced with new prescribed medications when the old one was only partly used.

And they just change, change, change and instead of maximizing what they're already on possibly sometimes they just change or add and they don't realize the patient's got all these scripts at home, maybe they got a couple of days a go. They paid thirty dollars and now they're useless. (Hospital Pharmacist)

Pharmacists reported regular encounters with people who had been discharged from hospital with little or no knowledge or understanding about what drugs they were prescribed – why, how and when they should be taken.

Service fragmentation

Patients and the family carers had talked of the time and money costs of service fragmentation and its affect on their ability to balance competing demands and manage co-morbidity. They resented and were confused by the inability of the health system to provide an integrated service, expressing frustration at poor communication and contradictory messages from health

care workers.⁶ The complexity and number of services and organisations providing care presented significant barriers to meeting peoples' needs.

All the health professionals agreed with these patients' views. Services operated across jurisdictions with no common planning or shared approach to care, and the streaming of care into clinical specialties created multiple lines of responsibility whilst removing overall accountability. From the health professionals' perspective, it created opportunities for fudging responsibility for care and for persistent blame shifting for failures.

Service fragmentation was often characterized by poor communication and muddled accountability within and between services.

They might have cardiac disease and also have renal disease and they might also have an endocrine doctor because they've got diabetes because they're all co-morbidities. And they don't really talk to each other which makes it really difficult and then you find patients who come in with ... things that don't make sense. (Hospital Pharmacist)

If we don't provide them with a discharge referral with information about that [medication] on them the GP has no idea what's going on; and often the patients don't understand. They're like 'well why did they change your medication?' And 'I'm not sure'. (Community Nurse)

Most health professionals expressed the view that the core of the problem was local and arose from difficulties in negotiating relationships between the various professions and services that contributed to each patient's care. They saw the health services as tribes operating entirely independently of each other, with little and erratic communication and minimal teamwork. One allied health professional illustrated the impact of this segregation. Describing a self-management programme initiated by nurses in a hospital setting, she observed that she and her colleagues would not refer to that program because:

'that's not something we social workers get involved in. It's more from nursing management'. (Allied Health)

All groups talked about the problems of moving information around the system in a timely and helpful way. These resulted from non-collaborative decision-making, poor communication between providers about decisions taken and the lack of an information 'store' where patient information could be held and made accessible to health care providers. Nurses, allied health staff and GPs all saw a need to increase the use of electronic tools and technical expertise to improve access to information for both patient and health professionals. Pharmacists particularly mentioned the need for core patient information to be available to prevent medication mishap.

Fragmentation of services led to costly inefficiencies caused by multiple assessments for access to similar services. When each health or care provider demands a new assessment of needs, flow is blocked and unnecessary costs created. Health professionals argued that rigid access pathways and competing jurisdictional accountabilities were exacerbated by the current remuneration structure. For example,

There are services out there that are available to patients but the only way these patients can get access to them is GP care planning, okay? So the only way they can see an exercise physiologist and get a Medicare rebate is if the GP fills the correct form out for them ... so I think that is very limiting. And I think that needs to be opened up to allow people to access those services without having to go through their GP ... that's very time consuming for the GP. They don't like filling the forms out because they say they don't have time, and they're very costly to the health service because every time that GP fills out that care plan they get paid \$250 to fill it out. (Community Health)

Health professionals had trouble referring patients to essential specialized or ancillary services. Opaque admission processes used by some high demand services were seen as allowing cherry picking of patients. GPs, in particular, were frustrated by circuitous and formal routes of referral and barriers to appropriate care; for example:

'just "getting past the receptionist" for specialist services.' (General Practitioner)

They resented the need to spend what they see as 'unpaid time' trying to overcome these barriers.

GPs emphasized their own role as the point of co-ordination for patient care. They argued that enrolling people with chronic illness in an agreed programme of care with a named primary care practice would ensure that the time-consuming care needs of patients with long-term conditions were met as well as adequately compensating the practitioner. Some were even prepared to consider a more radical shift from the Australian shibboleth of fee-for-service to capitation for registered patients. Most argued for increased remuneration to cover the time and complexity of managing chronic illness.

Some health professionals acknowledged that lack of teamwork had been noted by health care consumers as another key problem, contributing to service fragmentation. For example,

[Consumers] often express their concern that professionals aren't talking to each other, aren't linking up. It's very disheartening for them to go and see a GP in their community setting, try to see a podiatrist maybe privately, and a nutritionist somewhere else. And the question they often ask me is 'why don't these people ever speak to each other and co-ordinate my care?' (Nursing Manager)

While all health professionals talked about the importance of teamwork and multidisciplinary care they provided little information about what this would mean in practice: who, for example, would be doing what, and who would be paying for it. The most commonly expressed view was that 'someone else' should do something differently. Some other professional should, for example, send more timely letters of referral or discharge, better communicate changes to colleagues or consult before making changes to care. None of the groups explored how they themselves could contribute to better team working.

Health professionals' commonly held view was that fragmentation was a consequence of time and resource constraints; trying to meet unlimited needs with all too limited capacity. Some saw government intervention at national

level as the way to provide the whole of system resources necessary to overcome fragmentation but most focused on the resources needs of their own speciality.

In discussing this, the solutions they identified generally focused on a simple increase in remuneration or workforce rather than on structural change. The mixture varied according to their source of remuneration. GPs and community (retail) pharmacists, both groups working on a fee for service model, stressed time pressure within the current rate of remuneration – patients needed more time therefore appropriate care could only be provided if remuneration increased. Salaried health professionals, on the other hand, were more likely to argue for additional resources to increase services:

I'd keep it really simple, just give me some more nurses to go through the door, an educator, I'll have a psychologist, physio, don't need much – one or two social workers. I'll get that, and I'll have self-management plan happening and I'll get them [patients] self-managed. And I want some money for homecare. OK give me a little, so I can buy it in. And some sick leave and annual leave relief as well. No we don't ever get that ... Because it just cannot be done on the current resources. (Community Nurse)

Discussion

Health professionals largely agreed with patients on the problems people face when chronic illness invades their lives. There was a surprising consensus with near unanimity across all health professionals – rare in health policy discussion. However, this unusual amity extended only to the identification of problems. The analysis of solutions uncovered a great diversity of perspectives some of which suggested the barriers to policy reform.

Two general points emerged that are of strong policy interest. First, all but a small group of the professionals, irrespective of background, identified social and economic issues as key elements in patients' compliance. Patients, too, highlighted the social and economic cost of chronic illness but tended to describe them in immediate terms; managing the pressures of daily life and

the new burdens of disease.⁶ Most of the professionals, save a small number of GPs, believed that compliance would improve with more adequate pensions and safety net arrangements for pharmaceuticals and necessary aids. The international literature on chronic care¹² recognizes the effect of these financial barriers.

In addition to these financial barriers both health professionals and patients identified social context barriers, including the impact of poor community infrastructure, transport, affordable good quality food, and accessible facilities to improve and maintain health. These factors are not addressed in current health policy nor by the health professionals' suggestions in this study. Addressing them requires a level of inter sectoral action within and between jurisdictions which is more common, in the Australian context, in specific projects rather than system reform.

A second point of strong policy interest concerned the fragmentation of services. Patients were frustrated by the inability of the system to work efficiently and collaboratively in providing care.⁶ Professionals cited similar frustrations.

When asked about the problems they faced in providing care, health professionals pointed to failings of colleagues in other professional groups, for example citing obstruction of referrals or colleagues determinedly working in isolated 'silos'. Policy questions of accountability and cooperation are difficult to resolve by central mandate and there appeared to be little appetite to address it locally. For example, attempts have been made to improve collaborative care through policy by the introduction of Medicare fee-for-service items for chronic disease management. GPs are reimbursed for team care plans developed in consultation with allied health professionals. However, the uptake on the policy for team care plans has been disappointing – these items are claimed only half as often as items for management plans which require no collaboration. Referrals to allied health services subsidized under this team care plan programme are also low except in the already well-provided high socioeconomic areas – offering those possessing good access a further advantage.^{13,14}

Although GPs in this study believed continuity of care should start from the continuous relationship of individual patients to their GP, this form of coordination has been hard to deliver in Australian practice, not least because of heavy patient workloads¹⁵ and patients' freedom of choice of GP. The National Health and Hospitals Reform Commission, established in 2008 with a mandate to consider major structural reforms to the health system, has recommended improving the capacity of general practice to provide a focus on chronic care, including a system of voluntary registration of patients and improved accountability and quality and safety.¹⁶ However, their report does not address the problem of time and workload.

The health professionals in this study identified the need for national reform, though with little agreement on the detail. While they argued that Medicare should provide greater resources to those treating the chronically ill, this was limited, as stated, to a straightforward increase in funding with no structural change. There was little discussion about how Medicare incentives could be reshaped or change the way resources are allocated. Simply demanding increases in the volume of current services is unlikely to yield good results in the face of growing workforce shortages and mounting numbers of people with chronic illness.

Current Australian policy initiatives are driving change from a number of directions. These include: new organizational models for integrated comprehensive primary health care such as GP Superclinics (which have a similar intent to Canada's Family Health Teams¹⁷ or the NHS proposed polyclinics^{18,19}), the New South Wales HealthOne Pilots and a National e-Health Strategy²⁰ which includes making patient information accessible to other treating professionals; and specific initiatives like a common store of prescribing information and an increasing focus on inter-professional learning.²¹ These initiatives may provide some of the 'hard wiring' to support better health integration and co-ordination, the importance of which is made clear in this study.

The recent reform recommendations in Australia fail to address inter-sectoral connectivity between health and social care providers or between health policy and other government policy sectors such as income support and transport. Many examples exist internationally to support better integrative approaches, such as the cross-sectoral case management and coordination approaches of PRISMA in Canada, now being trialled in parts of France.²² Most importantly, the reform recommendations fail to identify mechanisms by which the perspectives of both health professionals and patients can inform and influence the shape of future health care in Australia.

The findings of this study give us a guide to what is seen as important and relevant to both health professionals and patients in achieving system improvement. Caution must be taken in generalizing the findings given a small sample size. However, our study helps researchers, health professionals and policy makers identify those policy spaces where more relevant and productive practices may develop. Understanding perspectives expressed by health professionals and patients helps define the challenges associated with structural reform.

Conclusions

The health care professionals in our study agree with patients about the main problems inherent in managing chronic illness. These problems, as well as ideas to improve the management of care are reflected in the content of policy at national and state levels. Despite this and considerable investment in possible solutions over the past 20 years, the problems remain. In primary care, introducing new MBS items (in the) 'hope that Australian general practice can adapt and deliver the required outcomes' has met with frustration.²³

Many of the suggestions made by health professionals in this study are addressed in health policy documents and clinical guidelines in Australia as in other similar countries. However, from the perspective of both people with chronic illness and health professionals the

picture is more complex than simply filling more resource gaps.

The challenge of chronic illness is made clearer by this study – high cost, complex, multi-provider care needs to be accessible, accountable and connected for both patients and health care providers. Facilitating this requires that policy do more than make statements about desired outcomes and focuses as well on implementation strategies that will lead to change. This implies recognition of the considerable constraint on change imposed by existing professional interests and the need for a reshaping of the relations both between the different health professionals and between health and other services.

While health professionals share patient perspectives about problems and have a strong understanding of the system problems that block effective care for chronic illness, their own professional perspectives strongly flavour their proposals for reform. A broader system view that incorporates the experiences of patients is necessary if policies are to remove the barriers to effective chronic care and better outcomes identified by both professionals and patients.

Conflict of interests

The authors declare that they have no competing interests.

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Ethics approval

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Authors' contributions

All authors read and approved the final manuscript.

LY contributed to study design, participated in the collection and analysis of data, designed and drafted the paper and revised the manuscript; JG participated in analysis of data, contributed to the design and drafting of the paper and the revision of the manuscript; Y-HJ contributed to study design; participated in the data collection and analysis and was involved in developing a conceptual framework for the results section, drafting (methods) and revising the full manuscript; JB participated in the collection and analysis of data, and was involved in revision of drafts of the manuscript; EL participated in the collection and analysis of data, and was involved in revision of drafts of the manuscript; SJ participated in study design and contributed to drafting and revision of the paper; MK participated in study design and contributed to drafting of the paper; CP-B participated in the collection and analysis of data and was involved in revision of drafts of the manuscript; TU contributed to study design, assisted in recruitment and data collection and contributed to data analysis and to drafting and revision of the paper.

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