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Caring for a marginalised community: the costs of engaging with culture and complexity

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Discussions about health inequalities have largely ignored a population of Australians who experience considerable health disadvantage related to discrimination and stigma — people of sexual diversity. The sexual diversity framework is inclusive, with a focus on lesbians, gay men, bisexual, transgender and intersex people, but also encompasses those who identify as heterosexual (some of whom may also experience same sex attraction).

Homosexually active men are affected by HIV infection at about 30 times the rate of other Australians.¹ In addition, there is emerging evidence that they are subject to a broader pattern of health disadvantage, resembling that seen in other stigmatised groups. High rates of depression, anxiety, substance-use problems and suicidality are evident in populations that experience social intolerance, including people of sexual diversity.² HIV, with its direct effects on people who are infected, the complexities of its clinical management, and the stresses it places on the social fabric of communities, further complicates the tasks of primary health care.

The Care and Prevention Programme (CPP) began in 1998 in response to a critical shortage of general practitioners with skills to care for people living with HIV/AIDS, and recognition of the importance of health promotion in the prevention of HIV (Box 1). It was established by a general practitioner, in partnership with community organisations, to provide care coordination and centralised access to a broad range of services for people with HIV and people at risk, with a focus on homosexually active men. The CPP's approach is based on the philosophy of primary health care outlined by the declaration of Alma-Ata³ (recently reiterated in the Adelaide Affirmation⁴), and recognises the shift to chronic disease care models for people with HIV.

Our evaluation provided an opportunity to assess the costs of care for members of a marginalised community, allowing reflection on the sustainability of primary health care programs and the application of the CPP approach in other settings. The investigation focused on the health needs of participants; the context and setting of the CPP; the models of care, financing and service

ABSTRACT

- The Care and Prevention Programme (CPP) began in 1998. It is based on the philosophy of primary health care, and has improved health among homosexually active men, including about a third of HIV-positive South Australians.
- The CPP was assessed using financial analysis and qualitative methods.
- Participants wanted to access care where they could feel comfortable and safe to talk about issues of sexuality and lifestyle.
- The CPP model is “economically” sustainable, but not “financially” sustainable within the Medicare Benefits Schedule. It is vulnerable to changes in political environment.
- The financing model for the CPP has been adapted by including state funding. General practitioners have adapted by lowering their personal incomes (but not quality of care). These adaptations have achieved fragile financial viability.
- Facilitators of sustainability for the CPP included:
 - It is part of the community that it serves;
 - The creation of deeply integrated networks of diversity-competent service providers; and
 - “Virtuous non-adaptability” of service providers in refusing to compromise care standards despite financial pressure to do so.
- Threats to sustainability included:
 - Difficulty maintaining a diversity-competent workforce skilled in HIV medicine;
 - Marginal financial viability; and
 - Political vulnerability.

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provision; and the financial effects on GPs caring for marginalised people under the Medicare Benefits Schedule (MBS).

Methods

A research question matrix developed by the Australian Primary Health Care Research Institute “hub” guided the investigation, which drew on the principles of Utilisation Focused Evaluation,⁵ and the tenets of Critical Ethnography (an anthropological method that explores how those who lack autonomy and are disempowered respond to their positioning).⁶ The research team met periodically to discuss insights arising from qualitative and quantitative data collection as it progressed. How new information related to previous data collected, and its implications for an evolving understanding of the sustainability of the CPP were considered. This approach is similar to the “action reflection cycle” or double-loop learning described in the education research literature.⁷

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1 The Care and Prevention Programme

- Focuses on people living with HIV and people at increased risk of HIV, in a sexual diversity framework
- Cares for about one-third of HIV-positive South Australians (202 people) and 431 HIV-negative people who may be at increased risk of HIV, including 380 homosexually active men
- Non-medical services, specialised general practice training and mentorship funded by the state Department of Health through Public Health Outcomes Funding Agreements (99%), and pharmaceutical sponsorship (1%)
- The University of Adelaide auspices the state-funded elements. Grants are sought annually and typically confirmed several months in arrears
- Attached to a general practice in an inconspicuous inner city location that provides a balance between central access and anonymity
- Collocated private practice provides GP care and some specialist consultations (with a gay-friendly psychiatrist and general surgeon) financed through standard Medicare Benefits Schedule mechanisms
- Most care takes place at the CPP centre, but support is also provided to a few GPs in other practices who are registered to prescribe HIV treatments
- The CPP provides services such as nursing, care coordination, dietetics, psychology, physiotherapy and massage therapy to form a comprehensive primary health care service
- The CPP assists participants to access culturally appropriate community services, including dentists, district nurses, and community support organisations
- The team meets weekly, over breakfast, to coordinate care, consider current issues and reflect critically on CPP activity ♦

Quantitative information on service utilisation and financial costs was extracted from the CPP database and practice management software. These data were the main input for a spreadsheet model that used conventional financial analysis to simulate practice activity under a range of conditions.

Qualitative data were derived from document reviews, as well as focus groups and interviews (undertaken by a non-clinical author, C B) with key informants, including CPP participants ($n = 17$), staff ($n = 7$), funding and auspicing organisation staff ($n = 7$), and other stakeholders in health care and health promotion for homosexually active men ($n = 13$). A semi-structured interview schedule was used, and sampling continued until saturation of themes was achieved. Interviews were taped and transcribed verbatim then subjected to thematic analysis by an author experienced in qualitative research (C B) and another author experienced in cultural competence (A L).

Two-way interaction occurred between themes arising from the qualitative and the quantitative analyses. This augmented and clarified the findings, and provided the integrated understanding needed to inform the larger debate about health care financing for marginalised groups.

Results

Document review indicated that the CPP has demonstrated measurable health benefits for participants, including significantly improved quality of life (Short Form 36 scores) and reduced prevalence of depressive disorders.⁸ Focus group interviews with

patients revealed that they not only sought high quality health care, but wished to access the health system in a setting where they could feel comfortable and safe talking about issues of sexuality and lifestyle.

The story of Alan (Box 2) highlights the issues gay men face in finding a GP with whom they feel safe. For many participants, mainstream general practice failed to meet this need. Recognition by funders and participants that the CPP can do so was a significant factor in its sustainability.

Primary care (as opposed to hospital) was the preferred setting in which to access health care:

[This setting is] more personal. I feel a lot safer there; lot more relaxed, because at the [hospital] you're sitting there and 30 other people around you are all dying and everything and it's a worry. It's just so depressing in there. [At the CPP] it's quite bright and happy and just relaxed. [I] feel safe going there. It's not as if you're going to catch anything in there . . . so that's what worries me about the hospital. — *Consumer Participant*

Financial effects of providing care in this setting

Half of the approximately 50 medical consultations per week with enrolled participants were Level B services (MBS item 23), and 43% were Level C (MBS item 36) (Box 3). These consultations lasted an average of 20 and 32 minutes, respectively. There was a disproportionately high number of Level C consultations compared with the Australian average, and the average duration of both Level B and Level C services was longer (Box 3).

The financial effect on a practice of having 50 consultations a week with patients of sexual diversity (as characterised by the CPP data) compared with average Australian patients was simulated (Box 4). The total revenue, GP income and practice income were all substantially lower on an hourly basis than the national average (Box 4). In Australia, 40% of revenue is typically used to cover practice costs. On this basis, the funds available for overheads from MBS sources were 35% lower than in a typical practice.

2 Vignette

Alan is a 48-year-old man who has been HIV-positive for more than 20 years. He identifies the importance of the gay community in his life; however, his life experiences have led to feelings of marginalisation in society and within the health system.

Living in the country, even finding a GP I could trust has always been a big problem. I go to the city every 6 months or so for tests, but have to keep everything dead quiet back in the community.

Alan has also felt marginalised within the gay community.

I've found attitudes to HIV in the gay community really depend on what circles you move in. There's a bit of resentment from younger guys.

It's nasty. You'd expect support from gay guys, but they can be quite awful.

Alan has also had many positive experiences within his community and within the health system. He uses a mix of service providers to ensure his needs are met. Since the Care and Prevention Programme began, Alan has been able to access a multidisciplinary team of diversity-competent health workers to meet his health care needs. ♦

3 Medicare Benefits Schedule (MBS) levels and consultation lengths: CPP compared with the national average⁹

	MBS item							
	Level A		Level B		Level C		Level D	
	CPP	Aust	CPP	Aust	CPP	Aust	CPP	Aust
Percentage of consultations	2.3	1.6	50.1	85.7	42.7	11.7	5.0	1.0
Average duration (min)	12	—*	20	12	32	28	45	—*

CPP = Care and Prevention Programme. Aust = Australian national average.
 *National data for the average duration for Level A and Level D consultations are not in the public domain. ♦

Despite this, qualitative data reveal a commitment by the GPs to provide a style of care that is associated with lower income per hour.

It's a different kind of practice and I think I'd have trouble doing this sort of thing elsewhere, or at least having a practice that accommodated me in doing that because of the financial disadvantages that it would bring to a practice... I think also this practice would only attract those that are genuinely interested in this type of work, working in this way, because there is no other incentive — not financial anyway. — *CPP health care worker*

Providing this care with the current MBS as the only source of revenue would not be sustainable, but this is due to reduced practice income per hour rather than any increased recurrent costs. This “financing gap” arises from an interacting array of factors, including:

- the proportion of patients who are bulk billed;
- the complexity of patients' needs;
- the GPs not compromising best practice, leading to longer consultations and hence a lower MBS rebate per hour;
- the need for support from a trained nurse, while at the same time less funding is available to the practice for overheads because of lower MBS income per hour of GP consultation;
- the effect of a culture that accepts “long consultations” on the duration of consultations practice wide;
- the strategy of some patients to see CPP GPs *only* when they have more complex requirements, rather than for shorter consultations that would (paradoxically) increase the practice's MBS income per hour; and
- the additional costs of training staff.

In the CPP's associated practice, this financing gap has been bridged by a combination of reduced GP incomes and savings associated with collocation with a state-funded service, to achieve marginal financial viability.

Non-financial effects of the CPP

Analysis of the qualitative data identified key facilitators of, and threats to, the sustainability of the CPP (Box 5).

The collection of data is a core activity of the CPP, and facilitates information flow between agents. However, some saw data collection as competing with service provision. The relationship with the University of Adelaide compounded these concerns, as it was seen to imply a focus on research and teaching over service provision. Others saw data collection as critically important.

A network of information flows has been established, in the pattern of a “centre of excellence”, which facilitates health worker education, including GP prescriber training, as well as professional support and reflective practice, through the weekly meeting.

Despite this, it was found that no single stakeholder held a “complete” or “true” picture, and that there were few completely shared understandings between stakeholders. Overlapping but non-congruent understandings of complex arrangements were common. The understanding of agents could be “usefully wrong”. For example, it was important for the funding body to be clear about the separation of the services provided under the umbrella of the CPP and by the associated general practice. However, for participants and for staff, this separation was unhelpful.

Discussion

The CPP provides care to people with complex needs who are marginalised in society at large, many of whom are also marginalised within the gay community. Marginalisation contributes to the complexity of their health needs across the biological, psychological and social domains. Traditional episodic, unidisciplinary, patient-initiated GP care fails to meet these needs adequately. Equally, as most are physically well, providing primary health care for all people with HIV in the tertiary setting would overwhelm specialised resources and compromise care integration.

The qualitative data indicated that, to be effective, primary health care for people of sexual diversity needs to be delivered in a culturally appropriate way. It must create a safe space in which they can feel comfortable to be frank and open about their health and their lives, without the disapproval and misunderstanding that

4 Financial effect of providing care to people of sexual diversity

	CPP	Australia*	% difference
Average consultation duration (minutes)	26	14	45%
Per 50 consultations			
MBS revenue	\$1915	\$1463	31%
Copayments	\$88	\$234	-62%
Hours [†]	22	12	82%
Total revenue	\$2004	\$1697	18%
Per hour			
Consultations	2.3	4.2	-45%
MBS revenue	\$89	\$124	-28%
Copayments	\$4	\$20	-79%
Total revenue	\$93	\$143	-35%
Effect on financial viability, per hour			
GP income available	\$56	\$86	-35%
Overheads available [‡]	\$37	\$57	-35%

CPP = Care and Prevention Programme. GP = general practitioner.
 MBS = Medicare Benefits Schedule. * All Divisions of General Practice.¹⁰
[†] As national data on average duration of level A and D consultations are not in the public domain, CPP durations were used as a conservative estimate for this analysis. [‡] Overhead at 40% of total income. ♦

5 Facilitators of and threats to sustainability

Facilitators of sustainability

The CPP is part of the community that it serves

There's a lot of people here who are gay identifying people, and it has been remarked to me... that there is a difference from this clinic and other general practices around Adelaide. Just the feeling of the place. They feel more comfortable and easier, even in the waiting room... I think it's because we are just very open and free and not concerned about sexuality. — *Health care worker*

I think what keeps the program going is basically the willingness of gay men to participate in that program... I think they really think that's going to help and I think that [the director] has promoted that program within the community as a good thing to actually do and people believe that. — *Funder representative*

Creation of deeply integrated networks of diversity-competent service providers

I often see people bring up things that without this forum [weekly breakfast meeting] people could be treating the same patient in two different areas and not really be aware of the problem that the other person has come up with... Many, many times when we've been discussing a particular case; that situation has been resolved because someone has been able to provide a vital piece of information. I see the meetings that are held here having a real benefit to the people and I think — well, I can't speak for everybody else, but certainly the impression I get from other people is that they find it valuable. I guess they wouldn't keep coming if they didn't. — *Funder representative*

"Virtuous non-adaptability" of service providers

Health care worker 1 [HCW1]: My personal approach to patients would be the same wherever I worked.

HCW3: Yes, I'd be the same as [HCW1]. I think I'd be the same whatever practice I go, but...

HCW1: But you have said that you wouldn't have the time to.

HCW3: They would not tolerate it. I would not be financially viable for anyone, not at the current rate of patients I'd see.

Threats to sustainability

Maintaining a diversity-competent workforce skilled in HIV medicine

I think that we have some fantastic people in this area that are in danger of burning out because there are so few of them and the problems are huge. — *Funder representative*

I think the patients in South Australia get fantastic care, that they don't realise how close their prescribers are to — you know, what a tightrope they're walking to be able to continue that care. We have had several discussions at the breakfast meetings about it only takes the dropping out of two or three people in South Australia and this sector would fall into a huge heap. — *Funder representative*

Marginal financial viability

I think what we would need to do as a state is to redefine what we need to buy, and probably look at collapsing some of those organisations and in some ways being given a bigger budget pool. In terms of Care and Prevention Programme though, I think that program is so interwoven with [the] practice that it's very difficult to actually pull them apart... so from financial viability point of view I think that makes that program really difficult. Because I'm not quite sure if the practice would be viable without the research bit of it and vice versa. — *Funder representative*

Getting connected with the university, I think, is a good approach. It means that those momentary problems don't become disastrous. The university or the government can say — gives you more flexibility to say "All right, we can tide you over for this one out of here and we return that later" sort of thing. — *Funder representative*

Political vulnerability

Well, initially what drove the first funding initiative was the fact that we had federally a bipartisan response... The driving of the funding issue since then has been — it's been a bit difficult of late because a typical public health response is that you put a lot of resources in... You succeed to a certain extent in reducing transmissions and keeping prevalence low and the typical response to that is that you then withdraw the resources. — *Funder representative*

In South Australia, for example, when you've got a government that's wanting to get a triple A credit rating... they make cuts... I'm not saying that's happened in this state, but those sorts of things can influence the amounts of money that get allocated to, say health programs... I mean while [HIV infections are] occurring in marginalised communities and they can call them groups like that — it doesn't matter whether they're Indigenous communities or gay and lesbian communities or injecting drug users — we've pocketed, marginalised these groups of people who are vulnerable for HIV and the rest of the population feels safe because they say, "I'm not gay and I'm not lesbian; I'm not Indigenous and I don't inject drugs so I'm not at risk."... We should have a pro-active prevention response to HIV in this country that doesn't rely on increasing transmissions in any part of the community, because it's wrong.

— *Funder representative* ◆

many have come to expect. It also requires engagement with the complex array of biological, psychological, social and political forces that bear on them and contribute to their health status. This complexity requires a team-based approach, incorporating a range of coordinated health and social services.

In the face of a national (MBS) financing structure that limits the capacity for a comprehensive primary health care approach, especially for diverse people with complex needs, how can the system and its participants adapt to remain sustainable? Adapting can be thought of as the process by which behaviour is modified as additional constraints are imposed (reduction in resources such as time) or additional opportunities become available (change in the evidence supporting best practice). A health provider's readiness to adapt practice and behaviour in response to change is generally seen as a "good" characteristic. However, if a GP is faced with a situation where adherence to best practice results in a reduction

both to their practice's and their own financial viability, should they adapt their clinical approach accordingly?

Alternatively, could "the system" or other agents adapt? First, the MBS could be adapted by:

- development of items designated for complex care, such as the Enhanced Primary Care (EPC) items and the payments for mental health or diabetes management;
- Practice Incentive Payments to compensate practices with reduced funding available to cover overheads due to longer consultation durations for complex care;
- opportunities for GPs to refer complex low-income patients to other MBS rebatable health care professionals;
- providing additional funding to expand the role of allied health professionals such as nurse practitioners in delivery of care to this group; or
- more fundamental reforms, such as capitation or fund holding.

The recent changes to Medicare have gone some way to meeting the additional funding required to provide primary care for *some* patients with complex needs. The MBS has recognised the need for supplementary payments for some chronic conditions, for geographical regions, for allied health professionals referred as part of EPC, for Aboriginal health care workers, and for after hours care. Alternatives are that GPs, the practice (overheads) and practice nurses can accept a lower income than they would receive in mainstream general practice; and compensatory support can be sought from other stakeholders (such as state health departments) to mitigate this gap, but at the cost of additional evaluation and contracting requirements.

For the CPP model to be sustainable, it needs to be more than financially viable. The model works because the CPP is part of the community that it serves. A community of people does not necessarily have geographic boundaries, but can be defined by values, behaviours, understandings and aspirations that are dynamic. A marginalised community is one that is assigned a subordinated position in society in relation to the dominant community and its norms. For subordinated communities, two main strategies are available to relocate their service needs: assimilation with dominant community norms (mainstreaming), or self-determination of their services and service delivery (niche creation or specialisation).¹¹

The political and economic maintenance of specialised services (even if chosen by the community) is associated with a cost: the need to justify its services and delivery models in the face of political shifts in the dominant community. That is, the capacity for sustainability intersects with vulnerability as a marginalised community.

The MBS has not adapted to care for people for whom traditional general practice is not culturally acceptable, although it would be feasible to include gay men or people with HIV in the EPC program. Instead, the financing model for the CPP has adapted by including Department of Health support, and GPs have adapted by lowering their personal incomes. A fragile financial viability has been achieved. However, the adaptive financing solutions that enable best practice care at CPP engender a political vulnerability that is not experienced by mainstream practices, which can be funded through MBS and patient copayments alone, regardless of the quality of the care provided.

This evaluation demonstrates that the main requirement for additional support arises from the lower per-hour income generated by GPs in the practice, not from additional financial costs of best practice care on a per-hour basis.

In an innovative financing model to ensure best practice care for patients with complex sociocultural and medical needs, under the constraints of a non-adaptive MBS, the ex-MBS support will always be seen as “additional funding to a special group of patients” rather than an indicator of the extent of the per-hour penalty borne by practices and GPs. In contrast, if the care were enshrined in Medicare (as for after hours care or diabetes), the funds would be seen as “appropriate compensation for the additional time GPs require to provide care for complex patients”. This exposes the myth that supporting specialised services “privileges” marginalised communities.

In other words, this model, which is economically sustainable in that it provides demonstrated health benefits for people of sexual diversity at similar total monetary cost to lower quality care, is not financially sustainable within the MBS and is institutionally vulnerable within a changing political environment.

It is clear that the Australian health system of fee-for-service under the MBS (“universal” health insurance) may serve average Australians quite well, but serves marginalised Australians poorly. Caring for people whose lives are made complex by marginalisation does not cost more; it ought to cost the same.

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Competing interests

Gary Rogers and Joy Oddy are employed through the program that is the subject of this study.

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