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## Care Centre visits to married people living with HIV – An indicator for measuring AIDS -related stigma & discrimination

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**Care Centre visits to married people living with HIV – An indicator for measuring AIDS -related stigma & discrimination**

Journal:	<i>AIDS Care - Psychology, Health &amp; Medicine - Vulnerable Children and Youth Studies</i>
Manuscript ID:	AC-2006-06-0024.R2
Journal Selection:	AIDS Care
Keywords:	HIV , AIDS, Stigma, Discrimination, Measurement



<b><i>N</i> = 230</b>	<b>Characteristic</b>	<b><i>N</i> (%)</b>
<b>Gender</b>	Male	128 (56)
	Female	102 (44)
<b>Location</b>	Urban	95 (41)
	Rural	135 (59)
<b>Infector</b>	Spouse	97 (42)
	Non-Spouse	133 (58)
<b>Age<sup>a</sup></b>	< 35 yrs	119 (51)
	> 35 yrs	111 (49)

Table 1. Demographic Population. <sup>a</sup> See Table 2 for further breakdown.

Age Category (yrs)	<i>N</i> (%)
<15	0 (0)
15-19	1 (1)
20-24	8 (3)
25-29	47 (20)
30-34	61 (27)
35-39	54 (23)
40-44	32 (14)
45+	27 (12)

Table 2. Original Age Categories.

For Peer Review Only

	<b>Category (Consolidation Code)</b>	<b>Attendant(s) <i>N</i> (%)</b>	<b>Visitor(s) <i>N</i> (%)</b>
1.	Spouse (A)	121 (53)	16 (7)
2.	Mother (A)	33 (14)	21 (9)
3.	Father (A)	17 (7)	7 (3)
4.	Child(ren) (A)	13 (6)	1 (1)
5.	Sibling(s) (B)	19 (8)	0 (0)
6.	Other Relatives (B)	0 (0)	38 (17)
7.	Friends (B)	0 (0)	7 (3)
8.	Positive Network (B)	11 (5)	29 (13)
9.	None (C)	16 (7)	111 (48)

Table 3. Recorded Attendants and Visitors.

<b>Category (Code)</b>	<b>Attendant(s) N (%)</b>	<b>Visitor(s) N (%)</b>
Immediate Family (A)	184 (80)	45 (20)
'Extended' Family (B)	30 (13)	74 (32)
None (C)	16 (7)	111 (48)
B + C	46 (20)	185 (80)

Table 4. Consolidated Attendants and Visitors.

For Peer Review Only

Attendant Factors	Mother (%)	Father (%)	Parent (%)	Spouse (%)	IF (%)	EF (%)	None (%)	EF & None (%)
<b>Male</b>	16 (13)	10 (8)	26 (20)	74 (58)	103 (81)	20 (16)	5 (4)*	25 (20)
<b>Female</b>	17 (17)	7 (7)	24 (24)	47 (46)	81 (80)	10 (10)	11 (11)*	21 (21)
<b>Urban</b>	12 (13)	7 (7)	19 (20)	51 (54)	74 (78)	16 (17)	5 (5)	21 (22)
<b>Rural</b>	21 (16)	10 (7)	31 (23)	70 (52)	110 (82)	14 (10)	11 (8)	25 (19)
<b>Spouse INF</b>	16 (17)	5 (5)	21 (22)	46 (47)	76 (78)	11 (11)	10 (10)	21 (22)
<b>Non-Sp INF</b>	17 (13)	12 (9)	29 (22)	75 (56)	108 (81)	19 (14)	6 (5)	25 (19)
<b>&lt;35 (yrs)</b>	16 (14)	9 (8)	25 (21)	61 (52)	92 (79)	16 (14)	9 (8)	25 (21)
<b>&gt;35 (yrs)</b>	17 (15)	8 (7)	25 (22)	60 (53)	92 (81)	14 (12)	7 (6)	21 (19)

Table 5.

IF = Immediate Family EF = 'Extended' Family Non = None

Spouse INF = Spouse Infector Non-Sp INF = Non-Spouse Infector

\* Indicates  $p < 0.05$ .

Visitors Factors	Mother (%)	Father (%)	Parent (%)	Spouse (%)	IF (%)	EF (%)	None (%)	EF & None (%)
Male	7 (6)*	7 (6)*	14 (11)	13 (10)	27 (21)	34 (27)*	67 (52)	101 (79)
Female	14 (14)*	0 (0)*	14 (14)	3 (3)	18 (18)	40 (39)*	44 (43)	84 (82)
Urban	7 (7)	3 (3)	10 (11)	7 (7)	17 (18)	37 (39)	41 (43)	78 (82)
Rural	14 (10)	4 (3)	18 (13)	9 (7)	28 (21)	37 (27)	70 (52)	107 (80)
Spouse INF	12 (12)	0 (0)*	12 (12)	3 (3)*	16 (17)	42 (43)*	39 (40)*	81 (84)
Non-Sp INF	9 (7)	7 (5)*	16 (12)	13 (10)*	29 (22)	32 (24)*	72 (54)*	104 (78)
<35 (yrs)	9 (8)	2 (2)	11 (10)	6 (5)	17 (15)	43 (37)	57 (49)	100 (86)
>35 (yrs)	12 (11)	5 (4)	17 (15)	10 (9)	28 (25)	31 (27)	54 (48)	85 (75)

Table 6.

IF = Immediate Family EF = 'Extended' Family Non = None

Spouse INF = Spouse Infector Non-Sp INF = Non-Spouse Infector

\* Indicates  $p < 0.05$ .



Care centre visits to married people living with HIV – An indicator for measuring AIDS -related stigma & discrimination

Keywords (5): HIV, AIDS, Stigma, Discrimination, Measurement

Word Count: 3025

**Abstract**

We tested whether observation of the presence and relationship of attendants (i.e. those that accompany upon admission) and visitors to a sample of 230 (128 male, 102 female) married HIV-positive people in an HIV care centre provides an indicator of caregiving AIDS-related stigma and discrimination. Sensitivity to gender, location (urban vs. rural), age (<35 yrs vs. >35) and source of infection (spouse vs. non-spouse) – factors considered to modulate AIDS-related stigma and discrimination were assessed.

HIV-positive people were accompanied by their spouse (53%), mother (14%), father (7%), with only 7% attending alone. Immediate family most commonly accompanied on admission (80%), but visitors were mainly from the ‘extended’ family (32%) with many receiving no visitors (48%). Females (11%) were more likely than males to attend alone (11% vs. 4%; p<0.05). No effect of location, age or infector was obtained.

Females were more likely to be visited by their mother (14% vs. 6%; p<0.01) and non-immediate family (39% vs. 27%; p<0.05) than males were. In contrast, fathers (0% vs. 6%; p <0.05) and spouses were less likely (3% vs. 10%; p<0.05) to visit females than males. No effect of location or age upon visitation was obtained.

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Non-spouse infected persons were less likely than spouse-infected to be visited by their spouse (3% vs. 10%;  $p < 0.05$ ) but more likely to receive ‘extended’ family visitation (43% vs. 24%;  $p < 0.01$ ). Spouse-infected persons had a higher rate of no visitors than persons not infected by their spouse (54% vs. 40%;  $p < 0.05$ ).

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Observation of the presence and relationship of attendants and visitors to HIV-positive people has potential as an indicator of caregiving AIDS-related stigma and discrimination. The measure appears particularly sensitive to the gender of the HIV-positive person. Such a measure may aid healthcare professionals to focus resources such as relational counselling upon the family and close friends of people experiencing AIDS-related stigma and discrimination, with the aim of improving the provision of care within the community.

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## Introduction

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In India, stigma defined as “...a powerful social label, stemming from a discrediting attribute of the individual, which radically changes their social identity...” leading to discrimination defined as actions “...we exercise through which we effectively, if often unthinkingly, reduce his [sic] life chances...”(Goffman, 1963) is all too common. Stigma via social marking precipitates and legitimises (to the actor) negative behaviour (Reidpath, Brijnath & Chan, 2005) such as social ostracism, prejudice and violence (Herek, Capitanio & Widaman, 2003). This situation is particularly apparent for people living with HIV (Aggleton & Warick, 1999; UNAIDS, 2003), in part due to its perceived

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link to immorality (Herek, Capitanio & Widaman, 2003; Poindexter & Linsk, 1999; Wight, 2000). In fact the stigma and discrimination directed at people living with HIV is considered to be one of the social roots of the pandemic (Parker & Aggleton, 2003; Piot, 2003).

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Most of the work investigating the perception of HIV-related stigma has understandably focussed on the person living with HIV, termed 'personal stigma'. Recent attention has turned to the stigma and discrimination experienced by (non-professional) caregivers, family and close acquaintances (Demi et al., 1997; Poindexter & Linsk, 1999; Wight, 2000). This reflects the fact that stigma can impose severe hardships not only upon those actually or perceived to be infected, but also their associates, carers and social groups (Herek, 1999; Schiff et al., 2003). Carers may, due to their relationship to an HIV-positive person, experience 'courtesy stigma' (Goffman, 1963) or 'guilt by association' (Powell-Cope & Brown, 1992). Association stigma and discrimination may be exacerbated by actively (and openly) caring for the HIV-positive person. This may affect the feelings and actions of the caregiver which is in turn perceived by the HIV-positive person. As such there is stigma placed upon that caring relationship – the caregiving dyad, which is unique but dependent upon the overlap of stigma felt by each individual (Wight et al., 2006).

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HIV-related discrimination indicated by action or omission, whether intentional or unintentional, direct or indirect can adversely affect HIV-positive people's access to treatment, work and education (Gostin & Mann, 1994; UNAIDS, 2004). This paper shall

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focus upon AIDS-related discrimination, reflected in an absence of caregiving behaviour from those closest to the HIV-positive person. In India, as in many other societies the primary carer of an HIV-positive person is most often a family member. HIV-positive status can place severe stresses upon the carer and family functioning in general (Land & Hudson, 2002; Powell-Cope & Brown, 1992; Wardlaw, 1994; Wight, LeBlanc & Aneshensel, 1998). Our belief is that an absence of care provision may (at least in part) reflect AIDS-related stigma and discrimination that are all-pervasive in India (Bharat et al., 1998).

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As recognized by Wight et al, estimation of perceived stigma within the caregiving dyad is important for understanding how best to allocate resources aimed at alleviating stigma among individuals and families impacted by HIV (Wight et al., 2006). Overt questioning regarding any psychological issue can independently affect both its perception and reporting behaviour. Furthermore, formal questioning can be distressing, resource intensive and inappropriate for those in severe ill health or experiencing extreme stress.

Therefore, a simple, inexpensive and indirect method of identifying patients who may be experiencing severe AIDS-related stigma and discrimination within the caregiving dyad could enable health care providers to focus resources upon appropriate individuals and societies. Such identification requires the development of a simple indicator which accurately reflects the complex social phenomena (Clifford & Rixford, 1998; Spicker, 2004) of AIDS-related stigma and discrimination.

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In India, there is a strong cultural ethos of caring amongst the 'extended family', therefore an absence of such behaviour is more likely to be evidence of stigma and discrimination upon the caregiving dyad than in the west, where significant care is often provided by state-managed or by the charitable sector, with relatively limited input from family and friends.

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We believe that observation and recording of those who attend upon admission, and those that visit HIV-positive people may reflect the extent of AIDS-related stigma and discrimination experienced within the caregiving dyad. Such a measure should be sensitive to factors that influence AIDS-related stigma and discrimination, particularly gender but also location, age and source of sexual infection. Greater stigma is placed on HIV-positive people whom are women, who are rural (where poverty and insufficient HIV/AIDS education are more prevalent)(Wight et al., 2006), are older (Herek, Capitano & Widaman, 2003) and those who are considered to be the source of infection within a long-term relationship (marriage).

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## Objective

Our aim is to test whether simple observation of the presence and relationship of attendants and visitors to married HIV-positive people in an HIV care centre may provide a simple, inexpensive and indirect indicator of caregiving AIDS-related stigma and discrimination by assessing whether the measure is sensitive to gender, location, age and source of infection.

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**Methodology**

Data relates to 230 (128 male, 102 women) married HIV-positive people attending the HIV/AIDS Care Centre at the Madurai branch of the Family Planning Association - India over a 6 month period from May to October, 2005. Clients on entry to the care centre gave informed consent for collection of data relating to their care to be used for administrative or research purposes having been told that refusal would not affect the care they would receive. Observation by clinical staff was performed with recording of the relationship of attendants upon admission and visitors 'closest' to the HIV-positive person. Closeness was ranked with the spouse being number one; as a wife or husband is considered more proximal to an HIV-positive person than their mother or father due to the greater shared stigma, resources and life conditions (Wight et al., 2006).

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Only those HIV-positive people who were infected through sexual contact and married at the time of attendance were included in the analysis, thereby ensuring that all clients had the possibility of spouse visitation. Data was compared according to gender (male vs. female), location (urban vs. rural), age (< 35 vs. ≥ 35 years) and source of sexual infection (spouse vs. non-spouse). There was an approximately equal split between groups for each characteristic (Table 1). Statistical analyses were performed by Chi-Squared testing.

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**TABLE 1**

Many of the subjects were unable to declare their exact age, therefore approximate age was recorded in the following categories (Table 2). Both the mode and median age were in the 30-34 category, therefore age was subsequently broken into those younger than 35 years, and those 35 years and above (see Table 1).

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## TABLE 2

### Results

On admission HIV-positive people were predominantly accompanied by their spouse (53%), with the mother being twice as likely to attend as the father (14% vs. 7%), whilst a small number were without attendants (7%) (Table 3). Those classed as other (more distant) relatives were more likely to visit (17%) as opposed to more immediate relatives.

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Overall, whilst few attended alone (7%), many received no visitors (48%).

## TABLE 3

Consolidation of the observed attendant and visitor data was performed to yield 3 levels:

Immediate Family (A), Extended Family (B) and None (C) (Table 4). 20% attended without their immediate family and a further 13% without 'extended' family. Immediate family was most likely to be in attendance on admission (80%), however, subsequent visitors were mainly drawn from the 'extended' family (32%).

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## TABLE 4

### Characteristic Comparisons

Females were more likely to attend without being accompanied than males were (11% vs. 4%;  $p<0.05$ )(Table 5). No effect of location, age or infector upon attendants was obtained.

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### TABLE 5

Females were more likely than males were to be visited by 'extended' family (39% vs. 27%;  $p<0.05$ ). Females were also more likely to be visited by their mothers than males (14% vs. 6%;  $p<0.01$ )(Table 6). Females received significantly fewer visits from spouses (3% vs. 10%;  $p<0.05$ ) and fathers (0% vs. 6%;  $p<0.05$ ). No effect of location or age upon visitation was obtained.

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Non-spouse infected persons received more visits from their fathers, than spouse-infected persons (5% vs. 0%;  $p<0.05$ ). Non-spouse infected persons were less likely than spouse-infected persons to have been visited by their spouse than spouse infected persons (3% vs. 10%;  $p<0.05$ ). Non-spouse infected persons were more likely to receive 'extended' family visitation (43% vs. 24%;  $p<0.01$ ), whereas spouse infected persons had a higher rate of no visitors (54% vs. 40%;  $p<0.05$ ).

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### TABLE 6

In general, the attendants were predominantly drawn from within the immediate family, whereas visitors came from the 'extended' family, if at all.

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### Discussion



In general, the spouse was most likely to attend on admission, followed by the mother, then the father with a relatively few being unaccompanied. This pattern most likely reflects the primary caregiver who is in a time of crisis required to bring the HIV-positive person to the care centre. Whilst 7% were recorded as having attended alone, we have noted that a number of HIV-positive people appear to receive assistance to the clinic, but that those persons are unwilling to enter the clinic. Whilst we have not directly investigated this, such behaviour may indicate AIDS-related stigma where the caregiver may not want to be part of “HIV affected community”, which can often strain the caregiver-care receiver relationship (Pearlin et al., 1994; Wardlaw, 1994). In some cases whilst adequate care may be provided at home this is not extended ‘in public’ in an attempt to minimize the effects of stigma and discrimination upon themselves, or the dyad as a whole (Herek, 1999; Schiff et al., 2003).

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Once the HIV-positive person is admitted and receiving care, visitation is in effect voluntary and as such more liable to be affected by processes of AIDS-related stigma and discrimination. Visitation was more frequently performed by persons other than the immediate family, whilst many received no visitors whatsoever. This may reflect a lack of care provision relating to AIDS-related stigma and discrimination or alternatively that simply the primary carer(s) were ‘taking a rest’ from their stressful and demanding task (Land & Hudson, 2002; Powell-Cope & Brown, 1992; Wardlaw, 1994; Wight, LeBlanc & Aneshensel, 1998). Within Indian society, in our experience the former is the most likely as ‘taking a rest’ during hospital admission of a family member with a non-stigmatized illness would be frowned upon.

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Comparisons based on gender demonstrated that females were more likely to attend unaccompanied. Consistent with the fact that the spouse is the most common attendant, this difference is mainly due to fewer husbands, compared to wives attending at the time of admission. This replicates previous findings of greater male (husband and father) caregiving disconnection (Wight et al., 2006). Reasons for this may include the perception of gender roles yielding lower levels of care, the financial requirement to work, their own ill health and possibly a greater susceptibility to stigma. Interestingly, father accompaniment was not different, between genders, although in both cases the actual numbers were small. No effect of location, age or infector upon attendants was obtained suggesting that it is gender that affects attending behaviour with little or no contribution from the other measured factors.

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Females were more likely to be visited by their mothers and those outside of their immediate families than males were, suggesting lower general stigma. However, this finding is tempered by a lower frequency of spouse visits, probably for similar reasons to those stated for attendants. This finding also contrasts with the data showing that females are more vulnerable to AIDS-related stigma and discrimination within the community and the family, reflecting the lower status of women (Paxton et al., 2005). However, the current study was weighted towards the spouse and the natural parents of the person with HIV, thus it may have failed to take into account discriminatory behaviour particularly prevalent from the in-laws of females (Bharat et al., 1998). Furthermore, differences may have resulted from the fact that our sample contained only married people. Whether our

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findings apply to unmarried people is unknown, particularly as AIDS-related stigma and discrimination is considered to be significantly worse for unmarried women (Paxton et al., 2005).

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Significant differences in father visitation to non-spouse infected persons are difficult to interpret in view of the generally low rate of father visitation. Non-spouse infected persons are less likely to have been visited by their spouse but were more likely to receive 'extended' family visitation reflecting the absence of 'closer' family members and they also had a higher rate of no visitation. These findings may result from stigma relating to their apparent 'guilt', that leads to discrimination and lack of care but may also reflect an inability to deal with HIV-related issues within the immediate family. No effect of location or age upon visitation was obtained. Our indicator appears to be sensitive to gender effects and to a lesser extent infector, but was insensitive to location (Wight et al., 2006) and age (Herek, Capitano & Widaman, 2003). However, as our sample was relatively small, further studies are warranted.

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Recording of only the 'closest' relative may have led to a distortion of the data. For instance, when a spouse visits no account of parental attendance is taken. However, those 'closest' are most likely to act as primary caregivers and be subject to shared stigma (Wight et al., 2006) and therefore of greatest interest when examining the caregiving dyad. For instance, if a friend visits with a spouse or parent, then almost without exception it is the spouse or parent who is the caregiver and therefore counting the friend in our analysis would have been misleading. In our experience, broad caregiving

partnerships involving numerous people are rare in HIV cases - consistent with caregiving dyads being secretive and self-isolating in response to the fear of rejection (Nelms, 2002).

There may be many factors other than AIDS-related stigma that prevent attendance with, or visitation of HIV-positive people, such as their own health status, childcare, work, economic factors (Farmer, 1996) particularly if the caregiver themselves are HIV-positive (LeBlanc, London & Aneshensel, 1997). However, at the time of sampling no HIV-positive person, had their spouse admitted within the clinic. Attendance and visitation is dependent upon a host of factors relating to the HIV-positive person, the carer, their relationships and society as a whole. However, it is those within the caregiving dyad who are most likely to attempt to overcome such obstacles.

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Summation of the total number of persons and/or visits could have been performed. However, the duration of stay varied between clients, which would have had to be taken into account. Whilst this may provide interesting information regarding the level of overall AIDS-related stigma this may be misleading as frequency of caregiving in a crisis (eg: care centre admission) may be disproportional to that during non-critical times where other time and financial commitments may be given priority. Furthermore, stigma or the fear of it may prevent an individual visiting a client entirely, however if a visitation is made, then stigma is unlikely to play a role in subsequent visitation behaviour. Hence, we assert that the recording of the 'closest' person or total absence, provide robust measures of AIDS-related stigma and discrimination within the dyad.

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Thus, we suggest recording the 'closest' attendant and visitor provides a simple, inexpensive and indirect indicator of AIDS-related stigma that may aid the allocation of resources aimed at alleviating stigma and discrimination among individuals and families impacted by HIV. Such action could have positive effects on the lives of HIV-positive people.

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Further study could utilise a questionnaire assessment of stigma perceived by the HIV-positive person and the caregiver (Wight et al., 2006) and compare it with the observational data – information a good nursing team should be aware of. Furthermore, additional factors known to modulate caregiving, such as duration of care, household income, self-rated health may also be assessed. In this manner we might attempt to establish whether our measure accurately reflects AIDS-related stigma and discrimination – hence quantify its value as a simple indicator (Clifford & Rixford, 1998; Spicker, 2004).

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## Conclusion

In conclusion, observation of the presence and relationship of attendants and visitors to HIV-positive people in a care centre appears to provide a simple, inexpensive and indirect indicator of caregiving AIDS-related stigma and discrimination that is particularly sensitive to gender. Interventions such as relational counselling aimed at the family and close friends of the HIV-positive people identified may help to reduce stigma and discrimination, thereby improving the provision of care within the community.

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