The Global Importance of Including Mental Health Carers in Policy

Globally, there is growing awareness of the need to prioritise mental health as a development issue, with a historic step achieved by the inclusion of mental health in the Sustainable Development Goals. Less understood is the impact that providing care for people who are struggling with mental illness has on those who provide it. Drawing from the experiences of an organisation who works with mental health carers, this briefing highlights the importance of widening the global mental health agenda to include local carers' voices, greater government investment in mental health with social protection schemes for carers, flexible paid employment arrangements, and innovative mental health care actions.

Recognising mental health carers

Within a lifetime, one in four people will experience mental health problems, yet globally mental health is neglected and under resourced. This neglect is largely due to the stigma associated with mental illness perpetuated by inaccurate information that it is untreatable and the fear that individuals can be violent. People living with mental disorders suffer in silence and experience daily discrimination and violation of their fundamental human rights, such as being kept in isolation and being mentally and physically abused. Mental health carers are also not exempt from the stigma and discrimination that comes with mental ill-health, yet the crucial role they play is often ignored. 'Carer' refers to the main person responsible for the day-to-day unpaid care of the family member that has a mental disorder.

This briefing draws from Chhahari Nepal for Mental Health's experience with mental health carers in the country. It offers insights into the stigma and exclusion carers may face as they try to balance their unpaid care roles with paid work to make a living in a low-income country.

Economic and social impacts

A World Economic Forum report estimated that in 2010 the economic cost of mental illness across the globe was US$2.5tn, and this is expected to triple by 2030. Mental health affects productivity at home and in the workplace for the individual, their family and their carer. Reduced income and increased health-care costs impact individual and family financial situations that can create or worsen poverty.

Additionally, a strong link exists between poverty and poor mental health. An emerging global mental health advocacy voice argues that people who are poor and socially disadvantaged bear an unequal burden of mental disorders together with their adverse social consequences including exclusion from family and community. Current measurements of poverty fail to link with evidence relating to the social determinants of health and mental health. Within low-income countries, investment in mental health is low, and consequently most people receive no treatment whatever their mental health problem.

Evidence on the economic and social impact of mental health carers in

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low-income countries is limited, particularly when it comes to the impact of balancing paid work with unpaid mental health care. By situating mental health carers within the broader discussion on care and mental health, this opens up opportunities to address the impact of low pay while juggling caring with working in an environment of limited government service provision.

Mental health carers' lived experiences

Evidence from the day-to-day realities of mental health carers, as revealed by 31 mental health carers in an urban traditional low caste community in Nepal, reveals the financial and social challenges that carers face in the absence of government mental health services and social protection provisions. It illustrates their struggle to manage the complex dynamics within the family and community together with the irregular behaviour that can arise as a consequence of mental illness. The 12 women and 19 men offer insights into the perspectives of men and women as mental health carers, including societal gender expectations, discrimination and stigma, which isolate mental health carers where superstitions compound exclusion.

Low incomes for carers adds a further burden

On average, 21 of the carers who were interviewed and in paid work earn between US$39 and US$49 monthly, working in jobs such as laundry work, house cleaning and vegetable selling. The low earnings reflect the carers' low educational achievement or employable skills together with their poor self-esteem. The negotiation to earn and to care is challenging for the 15 men and six women carers in a context where mental health services are discretionary and limited. Medical treatment costs, excluding residential care, range from US$15–20 per month. Often treatment is not affordable. The remaining six women and four men carers are poorly prepared to access paid work, and are financially dependent on extended family members or earn from begging.

Paid work and the unpredictability of caring

Paid work provides subsistence on the poverty line of US$1.25 or below per day, for the majority of carers' families. The caring role presents competing demands to juggle the unpredictability of the caring role with the responsibility to earn. The mismatch of schedules can make the demands of paid work conflict with the requirement of the unpaid carer role to provide food and administer medication. Difficulties arise due to the incompatibility of a work schedule with being responsive to unpredictable behaviour as the mentally ill person tends to roam from place to place in the day or night and may be forced to move on by authorities or local communities. A hospital admission requires the carer to be in attendance for 24 hours a day. This presents the carer with an impossible choice – either to abandon paid work with the ensuing financial consequences or to find other unpaid carers able to cover the paid work schedule. Ultimately the carer faces the dilemma to abandon the person they are caring for.

One young woman's journey of economic survival and caring

Sister, a young woman, cares for her physically disabled mother and brother with severe mental health problems. Father left the family home and has remarried. Brother has lived on the street for seven years, any close contact with him is difficult. Daily, she takes food to a place he knows. Delight comes when she can see him. The challenge remains to initiate brother's treatment. Sister left education to care for the family then found paid work as a waitress. Juggling her paid work and being a carer is stressful. Sister participates in the carers' group and with this support she's gained confidence and returned to education. A sponsor provides financial assistance for the family and sister's education. Sister will be the long-term carer for mother and brother and with better education paid work opportunities will improve.

The limitation of government as NGOs fill the gap

The Government of Nepal's mental health services are limited; the mental health budget is 0.001 per cent of the national health budget. Services are increased, by non-governmental organisations (NGOs) and the emerging private health sector.

The government's commitment to social protection remains little more than

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rhetoric; the disability allowance is not claimed by any of the 31 families in the case study – bureaucratic obstacles make this too difficult. A government hospital 'poor fund' is embedded in bureaucratic requirements but is more accessible and can contribute to treatment costs. The lack of investment in mental health care adds an additional burden to carers already in vulnerable and precarious jobs as they care for a mentally distressed person.

In the absence of the government, NGOs are playing a crucial role in filling that gap and providing mental health carers with the support they need.

Chhahari Nepal for Mental Health is an NGO that promotes a holistic person-centred approach to support men and women mentally distressed found on the street and disconnected from their family. Through establishing relationships with the mentally distressed person and their carer, this opens up the opportunity to support stigmatised families to regain confidence and dignity to negotiate through complex relationships amid economic constraint. Strategies by the NGO are focused on support to help balance paid work with unpaid care to improve access to mental health treatment, reduce tense relationships and enhance economic survival.

Mental health carers' multiple burden
In low-income countries such as Nepal, mental health carers carry multiple burdens; the stigmas associated with mental health, poverty and gender can be experienced in different ways: a male carer is taunted because caring is perceived not to be a man's role, or a female carer becomes excluded due to the violent behaviour of her son. Further, economic survival, whether begging or to balance paid work with caring to ensure care for the mentally ill family member, adds a further burden.

The gendered dimension of caring
Contextually nuanced gender roles are an integral part of the carers' complex environment, as this impacts men and women differently. Amongst the 31 mental health carers in the study 11 men and ten women care for mentally ill men; while mentally ill women are cared for by eight men and two women.

Responsibility for the care of a mentally ill married woman can be problematic. On marriage the husband's family becomes responsible for a woman's care, but when a mental illness occurs she can be victimised and denied care. Reluctantly, her female family members may assume the care role if their husband's family allow.

While the majority of male carers are in paid work in comparison to six female carers, socially constructed gender roles affect male carers differently. Men are reluctant to be open about their caring role or join support group opportunities for fear of further stigmatisation. Consequently, men face a 'double stigma' as care work is considered women's work. Only women attend the carers support group and are found at ease with being the carer. Alternative one-to-one support is provided to accommodate the male carer's identity as the breadwinner rather than as the unpaid carer. These social understandings of gender roles impact upon men and women carers differently so the quality of care may be influenced depending on whether the carer is male or female.

A father negotiates his breadwinner and care roles

A father in paid work cares for his wife and daughter who both have mental health problems. Mother has depression and daughter an anxiety disorder. He struggles as a man in his role as carer and faces discrimination within his community. This prevents him from participating in the carers' group. Treatment for his teenage daughter was unaffordable and she was unable to cope with school. Tensions in the home were high. Father receives regular support provided in a sensitive way not to undermine his status as breadwinner. Daughter has financial sponsorship, receives regular treatment and attends school. With improved educational achievement daughter will be better placed for paid work. Mother and daughter regularly attend a weekly support group.

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Policy recommendations

Greater government investment in mental health care with increased government service provision is an urgent action. The economic cost of mental illness in low-income countries requires assessment with responsibility for mental health care shared across all government ministries. No longer should mental health remain a health ministry concern only.

Create opportunities for carers to be included and heard, within communities, NGOs, government, and international organisations, to influence mental health policy development and practice nationally and globally. In doing so, this will bring attention to diverse local contexts and socially constructed gender nuances together with socioeconomic status – mental health carers are not a homogenous group, and poor carers must not be forgotten.

Promote and facilitate a person-centred approach within mental health care implemented by NGOs to lessen isolation. With enhanced self-esteem the confident mental health carer is better placed to improve their quality of care and more prepared to influence policy development.

Incorporate social protection schemes in mental health policy. Effective, government-led social protection schemes are essential to ensure a safety net for men and women with a mental disorder and their carers. Rights must be respected so a mentally ill person or their carer is not reliant on borrowing or begging for survival. Access to social protection as cash payments is necessary as well as the provision for free residential treatment to guarantee 24-hour care.

Promote awareness of mental health in the workplace to address issues of stigma and discrimination. Workplace mental health programmes open up opportunities to enhance staff mental wellbeing and to create an environment to accommodate diverse mental health needs including those of carers.

Support flexible working schedules to be responsive to the needs of mental health carers who balance paid work with their unpredictable unpaid care role.

Encourage economic development to create employment opportunities for carers to ease them into first-time employment with graduated levels of support and training within public and private organisations. Contributing to mental health carers' confidence and skill development improves their prospects for longer-term employment opportunities.

Strengthen evidence on the relationship between mental health and economic survival and how it impacts on carers. A new mental health research agenda implemented by government, local and international organisations, and academics will provide urgently required evidence with regard to the complex local environments, gender dynamics and socioeconomic situations of mental health carers.

Within global mental health forums and networks promote the unique local perspectives that mental health carers bring. The multiple burdens carried by mental health carers in low-income countries due to limited government provision require specific consideration. Widening the global mental health agenda to include local carers' voices strengthens global mental health advocacy to be inclusive and to create opportunities for new innovative actions in mental health care.

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Further reading

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