

CARERS, STIGMA AND SOCIAL ISOLATION IN PSYCHOSIS Geraldine Mason

MY STARTING POINT

Observing negative perceptions about mental health carers which do not seem justified by the facts.

WHO ARE CARERS AND WHAT DO THEY DO?

Carers are not paid workers. They are 'family, friends and neighbours who provide unpaid care to someone who is ill, frail or disabled'. The economic value of the contribution made by carers in the UK is £119 billion per year (Carers UK, 2011).

5.8 million people are providing unpaid care in England and Wales, representing 10.3% of the population (all health conditions). Of these,

- 3.7 million provide 1-19 hours per week
- 775,000 provide 20-49 hours per week
- 1.4 million provide 50 hours + of unpaid care, equivalent to a full time workforce larger than the NHS (Royal College of General Practitioners, 2013)
- 13% care for someone with a MH problem (NHS ICHSC Survey of Carers in Households 2009-10)
- 1 in 200 people has a psychotic disorder; lifetime incidence of psychosis is about 2%
- 1 in 10 people with psychosis commit suicide (Partners in Care, Royal College of Psychiatrists)

HOW PEOPLE BECOME CARERS

'Carers don't choose to become carers. It just happens and they have to get on with it' (Carers Trust 2013).

Affluent areas have fewest unpaid carers. Areas with higher levels of unpaid care have higher percentages of people who are 'limited a lot' in daily activities by the demands of caring (Chris White, Office for National Statistics, 2013).

STIGMA AND MENTAL ILLNESS

Goffman defined stigma (literally a mark) as an 'attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one' (Goffman, 1963).

'Marks' of severe mental illness include: a diagnosis of schizophrenia, odd appearance or behaviour, gait or tremor suggesting antipsychotic medication, having a carer though of working age. The stigma process involves:

1. Distinguishing and labelling differences
2. Associating differences with negative attributes
3. Separating 'us' from 'them'
4. Status loss and discrimination (Link and Phelan 2001)

Carers are stigmatized 'by association': 'The problems faced by stigmatized persons spread out in waves, but of diminishing intensity' to relatives and mental health staff. (Goffman, 1963: 43).

HOW DOES STIGMA DEVELOP?

Social attribution theory: judgements based on culturally given stereotypes are generated preconsciously and automatically (Fiske 1998).

Assumptions (also held by some professionals):

- mental illness is just deviance
- carers have chosen this role i.e. have opted out
- service users and carers are the same
- family dynamics cause 'mental illness' (Laing, 1970)
- Black men are violent

STRUCTURAL DISCRIMINATION

Low status groups find it difficult to challenge downgrading and closure of services.

SOCIAL ISOLATION

Since the 1990s, building-based services e.g. day centres, drop-ins have been closing. Beresford (2008) observes a 'downgrading of care'; collective support is replaced by 'mechanical' individualised services. What is required to facilitate social networks?

- Services built on relationships not transactions
- Places for social interaction (Clifton, 2011)

CARER BURDEN

Carers face problems getting information about the condition of the person they care for. Service users may refuse consent for health professionals to give information on their condition. Breaches of confidence can lead to legal proceedings. (R C Psych, 2013).

Carer policy approaches:

- Carers as a 'free resource' (with negative outcomes for carer health, employment and finances)
- Carers as co-workers
- Carers as co-clients
- Services to enable carers to achieve independence (Glendinning and Arksey, 2008).

Relationship between service user and carer is important. Kuipers (2010) describes:

- Positive, accepting the service user as they are now
 - Critical and hostile, blaming the service user
 - Over involvement, idealising the service user
- Carers become socially isolated; 'the shame and stigma of mental health diagnoses can cut them off from ordinary social support and opportunities to confide in others'. Caregivers also assist service user recovery. Kuipers argues for specialist psychosis caregiver services to help carers cope with stress, exhaustion and distress.

CONCLUSIONS

Attitudes to caring are contradictory. The affluent can pay for care, but low status groups have difficulty challenging downgrading of services. Thus neither carers nor service users can benefit from a supportive community.