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Social Factors and Recovery: Out of the asylum but still a long way to go

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Abstract: Mental health interventions matter most where they result in improvements in the social lives of patients. Those resettled from the asylum preferred living in the community and experienced few adverse outcomes. Resettlement was undoubtedly institutional in nature, patients having little or no choice over where, when or with whom they moved. The underlying 'train then place' rehabilitation model persists to this day, with step-down towards independence contingent on the (re-)acquisition of daily living skills. Subsequent recognition of the importance of choice and person-centred care has led to interesting questions about this model. Emerging evidence suggests instead a 'place then train' approach, involving a rapid move to independent accommodation or to open job placement with support following as necessary. The relationship between service user and the professional providing care is critical for these optimistic person-centred interventions. It is therefore disquieting to observe declining continuity of care and care models that promote fragmentation of the care team.

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A challenge facing any author in this festschrift for Peter is choosing which of the many facets of his work on which to focus. Like myself, Peter is of the generation that experienced the wholescale transformation in mental health services in England. By the time he qualified as a social worker in Manchester, the closure of the hospital asylum system and its re-provision through an array of community health and social care services had already been set as the future. In Manchester, Michael Silverman described a district psychiatric service with close primary care connections, that prioritised outpatient clinics, domiciliary visiting and day care, relying on just 100 inpatient beds for a population of 254,000 (Silverman, 1961). Four of eight of his colleagues each serving a population of approximately 250,000 said they no-longer needed the large mental hospital at all (Smith, 1961). Echoing these experiences, new principles of organisation and delivery soon followed. Hospital asylums were to be replaced by inpatient and outpatient health care provided across defined population 'catchment areas' in psychiatric units co-located with district general hospitals, with close liaison with general practice. The local authority would be responsible for the delivery of social care, including accommodation and day services. Multidisciplinary community mental health centres extended the reach of the psychiatric outpatient clinic and drove an expansion of mental health care to a far wider population than would have been involved previously.

Against this background, I thought first of Peter's work on help seeking and the role of primary care as a gatekeeper to specialist psychiatric services (Goldberg and Huxley, 1980) but decided in the end to focus instead on what has been most directly relevant to my time as a rehabilitation psychiatrist delivering care to people with psychoses and other severe mental illness where a great deal of the effort has involved social care as much as it has the more biological aspects of treatment and where quality of life is as vital an aspect of outcome as is clinical improvement. Developing measures of QoL that could be included in evaluation of mental health interventions has been an important effort led by Peter and colleagues, from the development of the Lancashire Quality of Life profile (LQOLP - Oliver et al., 1997) to the shorter, Manchester Short Assessment of Quality of Life instrument (Priebe et al., 1999) both of which have been used in many investigations worldwide

Housing

Closing the asylum and the resettlement of the residents followed a 'train and place' approach in which patients were brought together in small groups and practised various aspects of living outside the hospital before being re-located to ordinary housing. The best-known evaluation of this process showed that while the move made little difference to clinical outcomes, patients preferred living outside the hospital, gained domestic and social skills and expanded their social networks. No adverse effects in terms of mortality or homelessness were observed (Leff and Trieman, 2000). But there is no doubt that the resettlement process was itself institutional. Patients went as a group with little or no choice over when or where they moved or over who accompanied them. Critics pointed to the likelihood that support staff who came from the institution brought with them the paternalistic, risk averse attitudes and practices that had contributed to the hospital closure movement in the first place. An early study carried out by Peter and his colleagues interviewed 120 service users across a range of accommodations about their satisfaction with living arrangements. About a quarter expressed substantial dissatisfaction, particularly those living in group home settings. Although 60% acknowledged their ongoing reliance on staff, they nonetheless looked forward to a time of greater independence and saw the present arrangements as a temporary stop along the way (Hatfield et al., 1992).

Supported housing evolved slowly over subsequent decades but retained the basic rehabilitation approach with movements broadly conditional on acquisition of living skills. A large survey of the quality of care and experience of residents in supported accommodation was recently carried out across 14 nationally representative regions in England. Facilities ranged from 24-hour staffed residential units, through group homes and 'floating outreach' (people living in time unlimited, self-contained tenancies supported by visiting staff). As might be expected, the overall severity of mental health problems and costs for care followed a gradient, with the 24-hour staffed residential care settings being the most expensive and floating outreach the least costly with proportionally more residents with non-psychotic diagnoses. Interestingly, the objectively assessed quality of life (using the MANSA) was higher among residents of 24-hour residential care and group homes than among residents in floating outreach. This may reflect challenges faced by people coping with greater demands of independent living and correspondingly lower input from care (Killaspy et al., 2016). The graduated approach towards independent living has never been subject to experimental validation but is indirectly challenged by 'housing first' in North America. Here, the person is offered immediate placement in their own accommodation followed by care provided according to what they need to maintain the tenancy. The approach has been used to rehouse homeless people as well as for those with severe mental ill health and has been shown to have superior tenancy outcomes and no more adverse clinical outcomes than traditional approaches (Aubry et al., 2016).

From the earliest studies there also consensus that resident's satisfaction is greatest when care is delivered with dignity, respect and choice in a person-centred approach and where continued access is provided to a named support worker. Other aspects, including choice of residential location, neighbourhood 'fit' and engagement in some daily activity also feature but the personal relationship with staff remains key.

Occupation

Having some paid employment is an important aspiration of many service users. Having a job contributes to 'who we are' and provides a significant opportunity for friendship and benefits in terms of improving quality of life. The study by Peter and colleagues of 120 residents of supported accommodations referred to earlier, found only 10 people were in any kind of employment. Of the 59 people who responded to whether they would like help getting back to work, 29 (49%) said they would. Furthermore, while 75 attended some form of day care and reported satisfaction with this, most regarded it as just 'somewhere to go' or to meet people. It did not address their desire to achieve employment (Hatfield et al., 1992). The low rate of employment for people with severe mental illness continues. A survey carried out by Lloyd-Evans and colleagues (2013) found that only 5.5% of people with severe mental illness who were in contact with a community mental health team in London, were in any employment, the majority of which was part-time work or in a voluntary capacity.

Rather like the story of accommodation, the response of mental health services was initially to implement a 'train then place' approach that focused on identifying disabilities and deficits that had to be corrected before job placement. Very few of the workers in these sheltered employment schemes moved on to find employment. Paradoxically they may even have served to reduce opportunities, the comfort of predictable routine taking the place of the desire to move on and the associated risks.

A possible exception to this sorry tale was the Clubhouse model that emerged in the USA. Central to this was the 'work ordered day' in which attendees had the status of club members and as such, were expected to play a part in the running of the clubhouse. Members were also encouraged to take up 'transitional employment offers' – jobs in the open market but which were negotiated by the Clubhouse and in which job-sharing between members was encouraged. There was the expectation that these jobs would ultimately lead to open employment, paid at the going rate and held with all the usual rights and responsibilities of ordinary employees. One of the very few quantitative evaluations of the model compared 38 clubhouse members with a diagnosis of psychosis with a comparison group of 38 people attending other psychiatric services and matched on diagnosis, gender and age (Warner, Huxley and Berg, 1999). While at the outcome assessments at 1 and 2 years more of the clubhouse group were in employment than those in the comparison, the difference was not statistically significant. However, those in the clubhouse showed significantly greater improvement in quality of life scores especially on items of global well-being, finances and safety. Notably, 92% reported having a close friend compared with 62% of the comparison group. Service utilisation and costs also favoured the clubhouse group though largely for those in employment. Criticism of the transitional employment approach as just another example of 'train then place' – rather ignoring the positive results in terms of wellbeing, overall quality of life and social support afforded by the clubhouse.

The poor achievement of traditional vocational rehabilitation led some researchers in North America to experiment with a radical approach that goes straight to paid employment in ordinary jobs (i.e. not subsidised) with support added to help the person manage the demands of work. Such supported employment (SE) has particularly strong research evidence in terms of getting people into ordinary jobs as shown in a systematic review of which Peter was a co-author. This review showed that as many as a third of participants in receipt of a supported employment intervention had achieved competitive employment at 12 months compared to just 12% of people in receipt of traditional prevocational training (Crowther et al., 2001). At the time of writing, there were no large trials of SE in the UK and the authors cautioned that it was uncertain whether SE would maintain the advantage when applied to countries with more generous welfare provision or where the economy was less 'dynamic'. In fact, this reservation was prescient. Peter and colleagues carried out one of the earliest and largest randomised controlled trials of SE in the UK. Two hundred and nineteen people who had suffered from severe mental health problems for at least 2 years and were currently unemployed were randomised either to SE or to treatment as usual (that included access to a range of existing pre-employment vocational services). The scheme was provided by experienced employment specialists. The results were hugely disappointing. At the 1 year follow up, few participants in either arm had achieved employment. There was no difference between the groups in terms of the median number of hours worked each week, the number of jobs obtained, length of job tenure or median salary. The rates of open employment were broadly consistent with employment rates in the UK more widely. There were no significant differences in other measures including wider quality of life (Howard et al., 2010). At a 2 year follow up although significantly more of the intervention group participants had obtained paid work than those in the comparison arm (22% v 11%) the rates were still very low in comparison those achieved by other international controlled trials. Of those who had jobs, the median number of hours worked per week were higher in the control group and as before, there were no significant differences in any secondary outcomes including overall quality of life (Heslin et al., 2011).

In reflecting on the failure to replicate international findings, the authors wondered again whether this might reflect differences in the labour market and welfare support between the US and UK. That the intervention followed closely on the 2008 recession and its aftermath might well have played into this. Richard Warner in his classic review of historical trends in the outcome of schizophrenia, showed that outcomes were worse in times of austerity, paralleling prospects of employment for people with a diagnosis of schizophrenia (Warner, 2004). The SE specialists in this study were not managerially embedded in the local mental health services and it is uncertain whether the intervention had the wholesale backing of the clinicians, some of whom may even have discouraged service users to enrol, fearing that job stress could trigger relapse. The latter is certainly a possibility. A later study looked at the impact of an educational intervention aimed at promoting SE in early psychosis. Two of four early intervention teams that already employed a vocational worker were randomised to receive a motivational intervention for clinicians focused on attitudinal barriers to employment. Significantly more service users in the intervention teams than in the comparison achieved employment in the subsequent 12 months, a finding upheld after accounting for clustering by care coordinator and adjusting for service user characteristics including previous educational and employment history (Craig et al., 2014).

While SE studies clearly show superiority in terms of achieving paid employment in ordinary jobs with few if any adverse health consequences, there is little information on whether they do much to address service users expressed need for social companionship.

Personal relationships

Personal relationships between an individual and their family, friends, neighbours, people in authority (including health workers) and their wider network lie at the heart of wellbeing and mental health but people suffering from severe mental illness are more isolated than their peers in the general population, mostly reliant on family, other service users and the professionals providing services (Harley et al., 2012). Several studies have noted positive correlations between MANSA total quality of life and positive reports of social network size, quality and empowerment on the one hand and negative associations with perceived devaluation, discrimination and rejection (Björkman and Svensson, 2005).

Poisonous relationships in childhood, later breakdown in trust, instances of abandonment, bullying and other personal traumas are widely acknowledged as playing a causal role in psychosis with life-long consequences on attachment, trust, and the capacity to maintain close relationships. Of course, the behaviours associated with mental disorder such as suspiciousness, persecutory beliefs and ‘negative symptoms’ of self-neglect, apathy and cognitive function all serve to foster rejection from others. It is, however, noteworthy that only around half of the variance in loneliness reported by people with psychosis is ‘explained’ by these clinical variables (Ludwig et al., 2020) and the emotional commitment to friendship is a better determinant of whether people with schizophrenia have friends (Harley et al., 2012). Of course, both contribute in a vicious cycle of increasing isolation and withdrawal (Gayer-Anderson and Morgan, 2013).

Loneliness, the subjective emotional state when the desired level of social interaction is not met, is reported 6 times more often by sufferers of psychosis than the wider population (Meltzer et al., 2013) and by as many as 80% of people affected by psychosis (Stain et al., 2012). Reports of loneliness in adulthood appear to mediate between childhood abuse, depression and a range of psychiatric disorders including psychosis (Shevlin et al., 2015). Loneliness might explain part of the higher rates of psychosis among residents of densely populated urban centres (Giacco et al., 2012) and when persistent is also associated with poorer personal recovery (Wang et al., 2018).

The quality of the personal relationship between service user and the professionals providing care may be crucial, especially for longer-term illnesses where regular ongoing contact and availability in a crisis is necessary to promote and maintain recovery (McCabe et al., 1999). Promoting and maintaining this link is very difficult given the turnover of community care staff and the relentless pressure to discharge from care all but the most severely disabled. That this can matter for patient outcome was shown in a study of the continuity of mental health care for severe mental illness in one NHS Trust. Pseudo anonymised data from 5552 service users with a diagnosis of schizophrenia and a database showing all their contacts with any member of a mental health team were examined to create an annual index of ‘continuity’ that could range from 1 where all contacts in a year were with the same member of staff to 0 when only a single contact occurred or where all contacts were with a different member of staff. This annual index was then compared to clinical outcomes measured with the Health of the Nation Outcome Scales (HoNOS) in the same time periods. This showed a significant decline in continuity over the past 11 years associated with a significant worsening in HoNOS scores in later years reflecting staff turnover in part the result of repeated reorganisation of teams providing clinical care (Macdonald et al., 2019).

While a great deal of evidence points to the importance of social isolation and loneliness in the outcome of psychosis, it is harder to come up with effective interventions for these social outcomes. Befriending services are seen as a possible way forward and have some empirical evidence for benefits in common mental disorders (Mead et al., 2010) but the evidence for psychosis is sparse. For example, a recent randomised controlled trial, participants with a diagnosis of schizophrenia received either access to befriending or were only given information about social opportunities. At the end of a year, participants in the befriending group had significantly more social contact though there were no significant differences in the primary outcome of overall daily activity, or in quality of life, or symptoms of illness (Priebe et al., 2020). Of course, the limitation of befriending within a research trial is the short period over which effects must be measured. As with all relationships, it may take a long time and a lot of 'testing' before trust is established.

Conclusions

Given the importance of these social factors in people's lives, it is surprising how little attention is paid to assessing change in these as an indicator of recovery. In their review of the outcome of schizophrenia before and after the economic crash of 2008, Huxley and colleagues (2021) note that the trends towards better recovery before 2008 were reversed after the crash. While this applied to both first episode and multiple episode cases, outcomes for first episode psychosis were better than for multi-episode psychosis, an observation that at least partially might reflect the increased investment in early intervention services. To this I would add that many early intervention services including those local to where I work, routinely include interventions that target social outcomes including employment.

To conclude, I share many of the views put forward in a recent editorial (Huxley and Poole, 2023), notably that outcomes of mental health interventions matter most where they result in improvements in the social lives and aspirations of our patients. Psychiatry is the poorer for ignoring this.

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