**How can we maximise the involvement of carers and families in managing enduring mental illness?**

**Introduction**

Individuals with enduring mental illness comprise a very heterogeneous group. Whilst the majority have a primary diagnosis of psychosis, individuals may present with other existing psychiatric conditions, including depression, personality disorder, autism spectrum, and substance misuse (Holloway, 2005). These individuals are also more likely to have co-morbid physical health conditions, such as cardiovascular disease and diabetes (Killaspy, 2018). However, one area of commonality between these individuals is social impairment caused by their enduring mental illness. These individuals typically require substantial support. One key source of support is from families and carers.

Historically, families have had little involvement in supporting individuals’ wellbeing and management (Svendsen et al., 2021). Medical teams viewed carers as troublemakers, overly demanding, or they just ignored carers outright (Rowe, 2011). Thankfully, attitudes towards families have improved over time, such that their inclusion in mental health management is now part of best practice guidelines (NICE, 2011). However, carers remain an oft neglected and under-supported group, who have the potential to provide significant support to the individual they care for if they can be appropriately involved.

8.8 million people are carers in the UK (Carers UK, 2019), providing an average of 24 hours of care a week (Hawken et al., 2018). Carers and families, from here onwards referred to as caregivers, play a crucial role in the long-term management of individuals with enduring mental illness. This can be through the provision of moral support, practical support, and by acting as motivation for recovery (Aldersey & Whitley, 2014). Despite the significant value they bring through their caring activities, caregivers can also sometimes negatively affect individual wellbeing. This may be due to being a source of stress for individuals, failing to understand the individual’s condition or exhibiting stigma, and in some cases forcing hospitalization (Aldersey & Whitley, 2014).

Due to this risk of negative impact on the individuals’ wellbeing, it is important to define what maximising involvement means. A key aspect of Rehabilitation Psychiatry, defined by Killaspy et al. (2005), is “[maximising] an individual’s quality of life and social inclusion by encouraging their skills, promoting independence and autonomy”. Caregivers attempting to fully involve themselves in supporting individuals may inadvertently deprive them of their independence (Aldersey and Whitley, 2014). Moreover, it is crucial to remember that caregivers commonly experience negative physical and psychological consequences of fulfilling a caring role (Hawken, Turner-Cobb and Barnett, 2018). As such, for this essay maximising caregiver involvement will be defined as providing maximum positive influence whilst simultaneously facilitating individual independence and autonomy, to a degree that is mutually beneficial, healthy, and sustainable.

With this definition, there are 3 key elements to maximising caregiver involvement: evaluating the caregiver’s ability to help, psychoeducation about the individual’s condition, and providing tangible support to the caregiver and individual. Together, these elements would provide the caregiver with the knowledge, confidence, and professional support necessary to engage and help the individual manage their mental illness. Rehabilitation services aim to achieve much of this already, however they are often stifled by over-subscription and under-resourcing. Therefore, there may also be scope for creation of a separate support service to relieve some of the pressure from Rehabilitation services and to minimise risk of individual readmission.

**Ability to help**

The first element, evaluating the caregiver’s ability to help, relates to the degree of support they can provide. Whilst caregivers may want to support their loved ones, it is important to consider the possibility that individuals may not welcome that. Cohen et al. (2013) interviewed 232 individuals with serious mental illness and found that 22% did not want family member involvement in their care. Several potential explanations have been provided for this, such as the potential loss of personal privacy, or individuals attempting to reduce the impact of their mental illness on the caregiver (Cohen et al., 2013). An alternate study suggested that some patients may resent having been forced to go to hospital by caregivers (Aldersey and Whitley, 2014) and therefore no longer want their input. In the worst cases, family members may have been involved in the development or maintenance of the individual’s ill health, possibly through trauma or neglect (Spratt et al, 2012; Seligman, 2014).

This emphasizes the need to obtain the individual’s consent and proper evaluation of the caregiver. Therefore, it is important to determine the health of the existing relationship and to ask the individual whether they wish their caregiver to be involved at this stage. Forcing unwanted engagement could result in negative consequences for both parties.

If the individual agrees to caregiver involvement, boundaries must also be agreed upon. As mentioned above, a core concept of Rehabilitation Psychiatry is promoting independence and autonomy (Killaspy et al., 2005). However, caregivers can struggle with this. Individuals may be the recipients of paternalistic and infantilizing behaviours and beliefs from caregivers, which may prevent them from exercising their autonomy (Aldersey and Whitley, 2014). Therefore, to maximise engagement safely, it is crucial to set boundaries, so that individuals can take responsibility and develop their own independence (Waller et al., 2018).

Boundaries may also be protective of the caregiver and empower them to refuse inappropriate demands from the individual and challenge harmful behaviours. One example of this would be with individuals experiencing substance abuse. In older adults, caregivers may become complicit in maintaining damaging behaviours through well-intentioned attempts to support or placate the individuals they care for (Benshoff and Harrawood, 2003) .This may also be due to underestimating the severity and harm of the abuse process because of how much it impacts emotionally on the caregiver. Therefore, setting boundaries can empower caregivers to address these issues to help prevent them from reinforcing negative behaviours.

To summarise, caregiver engagement can have both a positive and negative influence. Positive engagement relies on caregivers being appropriate sources of support, individuals consenting to their involvement, and both parties agreeing to respect defined boundaries. Importantly, this discussion can be facilitated by the healthcare team, to ensure that the optimum outcome, and therefore maximum involvement, is achieved.

**Psychoeducation**

The second element, psychoeducation, relates to educating the caregiver about the individual’s condition and how best to support them. Psychoeducation can provide caregivers with information about symptoms, treatment options, and recovery strategies for the individuals they care for. They are also empowered to encourage the individual to take medication and engage with services. Family psychoeducation has a strong evidence base and has been found to reduce individuals’ relapse and hospitalization rates, decrease burden on families, and improve quality of life (Lyman et al., 2014).

Psychoeducation does not aim to turn caregivers into active treatment facilitators, and few individuals want this (Waller et al., 2018). Instead, individuals want to communicate with them about their mental illness. Therefore, psychoeducation provides the background knowledge so that caregivers can meaningfully, and therefore maximally, engage with the individuals they care for.

Caregivers may also be educated on what support they can provide. Aldersey and Whitley (2014) identified 3 main forms of support: moral, practical, and motivation to recover. Moral support comprises of caregivers’ positive regard, and providing their comforting presence, physically or otherwise. Practical support is more tangible, and relates to financial assistance, transportation, and general help with activities of daily living. Motivation for recovery is a passive form of support. The presence of family provides an aspiration to make a family themselves or attempt to reconnect.

Psychoeducation is also valuable in teaching caregivers what pitfalls to avoid. Aldersey and Whitley (2014) also identified 3 barriers to individual recovery: caregivers acting as stressors, displaying stigma or failing to understand the individual’s situation, and forcing hospitalization. Family stress is derived from judgemental attitudes, being overbearing, and eroding the individual’s autonomy and independence. Stigma appears to be derived from a cultural view of mental illness, whereas lack of understanding originates from a deficiency in caregivers’ knowledge of the diagnosis and lived experience. Forcing hospitalization refers to caregivers escalating care to medical professionals by calling ambulances or taking individuals to hospital, or as the individual’s perceived risk of this scenario. This can be defined as both supportive and detrimental, depending on whether the individual view their hospitalisation as appropriate or not. Irrespective of whether hospital admission was appropriate, or whether individuals had insight into the necessity of this action, this scenario may influence the trust between individuals and their caregivers. This trust would therefore affect how receptive the individuals were to further caregiver input.

By providing adequate information and resources, caregivers can be empowered to communicate with the individuals they care for and learn to understand their condition and situation. They can be informed about what support they can provide, and what behaviours can be damaging. Therefore, by educating caregivers on how best to interact with the individuals they care for, they can be supported to engage maximally.

**Tangible support**

Caregivers can be a crucial form of support for individuals with enduring mental illness, however caregivers themselves also require support. Caring for an individual is physically and emotionally draining. Around 72% of carers have experienced poor mental health due to their caring role, whilst 61% have experienced physical ill health (Carers UK, 2018). Just some of the reported physical effects are back pain, gastric ulcers, headaches, and arthritis (Sawatzky and Fowler-Kerry, 2003).

Another key factor to consider is caregiver burnout. Gérain and Zech (2019) describe caregiver burnout as a tridimensional syndrome, consisting of emotional exhaustion, depersonalization, and reduced sense of personal accomplishment. This can result in caregivers feeling unable to continue providing support, becoming detached from the individual, and no longer finding their care work fulfilling or meaningful.

There is also a significant financial burden on carers, with 12% of people caring for a year or less entering debt, and 25% of people caring for over 15 years entering debt (Carers UK, 2018). Caregivers may be entitled to financial support through benefits such as Carer’s Allowance, or they may be eligible for support from local councils (Mind, 2021). These systems can be complex; therefore, a key element of caregiver support should be from a social worker who can facilitate applications to relevant organisations for support.

Clearly, caregivers are susceptible to a wide range of negative consequences from their caring role, covering medical, psychological, social, and financial domains. With such a broad array of issues, itis essential that adequate support is put in place to ensure caregivers remain healthy. If they do not, then not only has the engagement process actively caused them harm, which would be unacceptable on its own, but the sudden loss of caregiver support may significantly harm the individual too. Therefore, one solution may be to actively involve caregivers in discussions with the multidisciplinary team (MDT).

An MDT would have the broad expertise necessary to arrange and provide holistic support for both the individual and caregiver. Involving the caregiver in discussions would also permit them to communicate important information about the individual’s recovery directly to the team, and potentially be involved in determining what further management would be appropriate from their perspective. Involving the caregiver would also provide them with a sense of value and personal accomplishment, which may help reduce the risk of burnout. Therefore, encouraging individuals to invite caregivers to review meetings with the MDT, if the relationships are appropriate, may serve to promote involvement and better communication.

**In practice**

This essay has explained how maximal involvement of carers in managing enduring mental illness requires input from the individual, the caregivers, and the MDT. Rehabilitation services already strive to utilise many of the methods described previously. Unfortunately, significant resource pressures make it very difficult to achieve maximum caregiver involvement whilst adequately supporting them. One idea to supplement this would be the creation of a support pod or ‘1-stop shop’.

This concept is already utilised by the cancer charity Macmillan through their Macmillan pods. The pods are information and support centres situated in hospitals, libraries, and community centres for individuals with cancer and their families to seek support (Macmillan, 2022). They provide a range of services, including counselling, educational courses and resources, and financial support. The value of these pods is that anyone can attend drop-in sessions to receive a wide variety of support from easily accessible locations. An adapted form of this concept could be used for supporting individuals and their caregivers. The service could be designed to reinforce all 3 elements of maximal involvement discussed previously: concerns about the individual-caregiver relationship or changing care needs could be swiftly escalated to trained staff, educational courses and resources would be readily available, and staff would be available to provide medical, psychological, social, or financial support when required.

This is clearly a very resource-intensive service that would take substantial time and investment to develop. However, much like how Macmillan is a charity independent from the NHS, this service could potentially be run by independent mental health charities. Not only would this provide resources and expertise to help develop the service, but it could also relieve some of the pressures on Rehabilitation services by providing an external resource that focuses on reducing the risk of readmission.

With the creation of this service, it would be possible to implement the suggestions of this essay into a 3-step plan to maximise caregiver involvement in mental health management:

Step 1 would involve providing the caregiver with the knowledge to fully engage with the individual and the medical team. This can be achieved through providing psychoeducation as described previously. This also acts as an opportunity to build rapport between the caregiver and the healthcare team, and to potentially develop the relationship between the individual and the caregiver. Progression to Step 2 would be contingent on the wishes of the individual.

Step 2 would be the integration of the caregiver into care planning and management. This would take two forms. The first would be clinician-facilitated discussions between the individual and the caregiver. Each party could discuss what support would be appropriate, and set defined boundaries, whilst supervised by a clinician who could help guide the discussion. The second form would be involvement with the MDT to assist in care planning and to request bespoke support based on the requirements of the individual and caregiver.

Once this plan has been agreed upon and appropriate support is in place, Step 3 would involve putting the plan into action. Progress could be monitored through regular meetings with the healthcare team, or by the support pod. Both the caregiver and individual would be supported in making any necessary changes to the relationship or seeking additional support, ideally without the need for long waiting times. This way, any issues raised could be resolved swiftly and with minimal detriment to caregivers, individuals, and Rehabilitation services.

**Conclusion**

In conclusion, maximising the involvement of caregivers in enduring mental illness is complex and multi-dimensional. First, it is important to establish whether the relationship between caregiver and individual is beneficial and permits involvement, ensuring the patient consents, and setting boundaries as to what this involvement entails. Secondly, caregivers must be educated about the individual’s condition and how best to support them, whilst promoting their autonomy. Thirdly, caregivers should be offered tangible support from the MDT, whether they need medical, psychological, social, or financial support. Caregiver involvement may also prove beneficial to management planning by providing their perspective. Whilst complex, these elements may be best provided through the formation of a ‘1-stop shop’, where caregivers and individuals feel welcome to seek support with their relationship, understanding, or management. This may all be integrated into a 3-step plan, focusing on educating the caregiver, actively involving them in management, and providing readily accessible holistic support. Therefore, this may present the best opportunity for involving caregivers in mutually beneficial, healthy, and sustainable management of their loved ones.

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