

In Strong Hands: eHealth Support for Mental Health Carers

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ABSTRACT

The carer plays a pivotal role in management of and improvements in mental illness in patients. A stronger focus on caring for carers can help reduce relapse rates, hospital admissions and length of stay for patients. Many carers, however, find themselves unprepared for the difficult role of caregiving and feel unsure of where to turn for support. In this paper we discuss the importance of including carers in solutions for mental health support. We present the design and development of an innovative platform technology that aims to integrate mental health units, social workers, community services and the carers to support carers in providing informed quality care to people with mental illness.

Author Keywords

Mental Health, eMental Health, Mental Health Carers.

ACM Classification Keywords

J.3. Computer Applications, Life and Medical Sciences, Health

INTRODUCTION

Internationally, the recovery movement in the mental health field is continually striving towards increasing patient and carer participation in the design and delivery of mental health services [9]. There is increased recognition that people can and do recover from mental illness but also that people can struggle to recover from mental illness in isolation [20]. Concurrently, economic business model pressures within public hospital services are focusing on bed management to reduce the costs associated with long length of hospital stay and readmission rates. Contextually, the current discourse and construction of families within mental health policy and research has created the obligated

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caregiver role with associated expectations for responsibility for patient care [2]. Each of these discourses promote family and carer networks playing a pivotal role in the monitoring and stabilising of mental health symptoms; ensuring preservation of natural supports and acting as a safeguard against over reliance on hospital based mental health services.

Many people who experience severe and complex mental illness are supported by unpaid carers – partners, family, friends or community members. It has been estimated that up to 75% of people diagnosed with schizophrenia are living with their families or have regular contacts with them [12]. Carers take on roles, such as managing medication, monitoring mental and physical health, supporting activities of daily living, de-escalating risky behaviours, provision of emotional and financial support, strengthening and repairing interpersonal and social relationships as well as advocacy and navigation of services.

The burden of caring has been extensively researched within health fields, such as dementia [8] and palliative care [6], however the caring experiences within mental health, whilst heavily researched [11, 17, 19] are not as widely acknowledged in practice. Caring for people with mental illness can generate a wide range of experiences – both negative and positive and can include fear, guilt, shame, isolation and chaos, as well as purposefulness, pride and achievement [10]. Many carers, particularly working females [11], experience significant mental and physical health difficulties themselves due to the burden of caring for their unwell loved ones. Moreover, high carer burden levels have been found to be a predictor of poor long-term outcomes in first episode psychosis [15]. Studies have also found high levels of perceived neglect and dissatisfaction of carers of patients with Borderline Personality Disorder, with findings also showing that carers were generally unaware of support resources available for themselves [7]. Even in child and youth mental health settings, it has been found that the loss and grief responses of parents and carers are often not acknowledged or addressed by mental health clinicians [16].

Supporting improvements in carer wellbeing has proven to be effective in reducing relapse rates for mental health patients and the distress in their families [14]. There is a greater chance of avoiding the need to use restrictive

interventions and in reducing absconding rates [3], if family and carers are considered and included during treatment and planning. Two of the underpinning principles of Queensland Health Mental Health reform [5] are the recognition that consumers, carers and families have an important role in the recovery journey and that consumers and carers have very separate experiences and needs. Despite these commitments and findings, there is a paucity of evidence of routine assessment of carer wellbeing and targeted therapeutic intervention for carers in many mental health services.

The barriers to effective caregiving in family centered care have been identified as poor staff attitudes, unsupportive services, poor communication and inadequate information sharing [18]. Mental health carers have consistently reported a need for timely information and support particularly during times of crisis as well as quality communication and inclusion in relation to treatment decisions and options [13]. In addition, flexible means of engagement with carers are required due to a range of factors such as working commitments, availability during business hours, financial, distance and transport barriers and other caregiver responsibilities [13].

Mental health social workers are well placed to assess and support carers wellbeing, as well as strengthen family and carer networks to achieve best practice care but face aforementioned business model pressures and high demand of consumer need. The Australian Association of Social Work outlines the specific focus of social work in the mental health sector as being the person with a mental illness and their significant others, their social context and the bio-psychosocial consequences of mental illness. Furthermore, the purpose of mental health social work practice is to promote recovery and restore individual and family wellbeing [1].

The advent of digital technologies in health services allow the potential for an innovative, flexible system for supporting mental health carers. The technologies allow the pooling of available resources together with the integration of hospital, health, and community services. CSIRO's Australian eHealth Research Centre (AEHRC) and the Metro North Hospital and Health Service (MNHHS) are collaborating with community service providers to design and develop a platform technology that will unite the mental health unit, social work service and families network to support carers in providing informed quality care to people with mental illness.

KEY STAKEHOLDERS

Pivotal to uptake and ongoing engagement is user centricity. As such, the success of a platform technology to support mental health carers will be largely dependent on the input of relevant stakeholders. This collaboration will seek contribution from MNHHS, the largest public health service in Queensland, serving a diverse population approaching 900,000 people; Metro North Family and

Carers Network; families and carers that fall into three categories (early carers, first 12 months; mid term carers, up to five years; and long term carers, over five years) and the AEHRC, Australia's leading national research facility developing and deploying leading edge ICT innovations in healthcare to improve service delivery in the Australian health system.

PLATFORM TECHNOLOGY

The AEHRC has an existing platform technology, the 'care assessment platform' (CAP) (Figure 1) that will be modified specifically to support mental health carers. The CAP is the first clinically validated mobile health delivery of cardiac rehabilitation in Australia, tested in a randomized controlled trial at MNHHS in 2012 [21] and has previously been modified to support cardiac care in Indigenous communities [4].

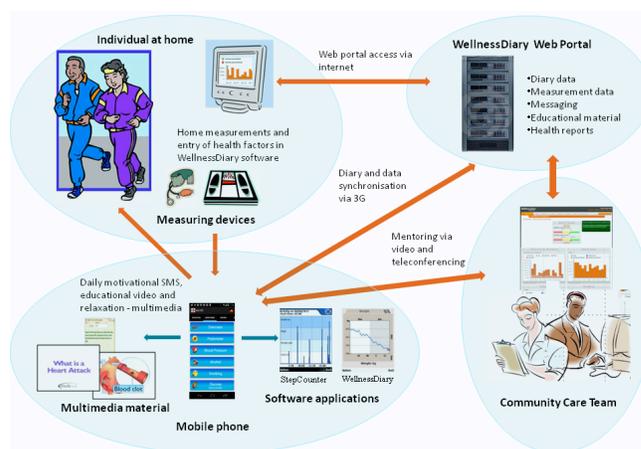


Figure 1 – The Care Assessment Platform for mobile health delivery of cardiac rehabilitation [22].

There are three main components to the CAP:

1. service delivery, encompassing enrollment, the clinical portal, home care program, and mentoring;
2. resources, comprising videos, articles and motivational messages; and
3. a smartphone application (app), containing a health diary and delivery of the educational material.

The existing platform will be used as a starting point to conduct a consultative phase with relevant stakeholders to modify the platform to support carers' needs in the mental health domain. This would include adapting the clinical portal, identifying and digitising appropriate resource materials, defining the stress related factors, and adapting the app to record these.

In this paper we describe the changes to all three components that will be required to make the program suitable for mental health carers. We outline the engagement process to gather and consolidate relevant resources and services and discuss delivery through both

Android and iOS operating systems. This ambitious project would benefit from input of the CHI community.

The Big Picture

On admission to the mental health ward of a consumer with severe mental illness (SMI), social workers from MN Mental Health Service enter the referred carer's information into a clinical portal, including perceived confidence in caring ability and their experience in caregiving. The carer is then provided with the wellness app and shown how to access resources that may be useful in the initial stages of care post crisis. Within seven days of discharge, the social workers begin a weekly regime of mentoring phone calls to carers for a period of six weeks, followed by ad hoc calls as required. Carers use the app to record stress-related factors that may impact their ability to provide care. The wellness data is automatically uploaded to the clinical portal. Prior to the weekly phone call, social workers can review the previous week's data to identify warning signs of increased carer stress or indicators that community services are required. In addition, this data will identify factors indicating that the patient's mental health status is declining and may require preventative intervention.

Developing an Appropriate Service Delivery Model

One of the challenges with the current model of mental health care is the lack of systems to bridge the gap between mental health units and social work services. It is therefore paramount that this platform provides such connection.

In consultation with mental health workers, social work clinicians and carer stakeholders, an appropriate program for smartphone-based delivery will be developed including peer and clinical education, journey tracking, motivational messaging and mentoring sessions; all of which carers can access at a time and in a place convenient for them. The service delivery component is supported by the clinical portal which contains data that forms the basis of the home care program and is accessed by mental health social workers. Over the program period, each carer is assigned a mentor from the Social Work Network, with scheduled consultation and counselling via weekly mobile phone/video calls. Educational resources developed in consultation with the Family and Carers Network will be provided through the app.

Provision of Resource and Motivational Material

To increase awareness of mental health resources and risk factors for patients and carers, educational information is delivered via video, including vignettes of stories of hope and wisdom from experienced carers. Motivational and educational text messages are sent to the carer's phone. The educational and motivational material is specific to the carer's requirements, and delivered as appropriate throughout the program. Mentors can mete out material based on progress of the carer's journey. Messages will also be used to convey information for the carer on new

services, and allow carers a voice in service delivery. Information from the Family and Carer Network will be uploaded into the app to form a resource library for carers. Targeted referrals for individual carer needs can also be made from this point.

Customisations to the Mobile App

The health app is integrated on the carer's smartphone. The app allows the carer to make and track data entries of their health and wellbeing without impacting on their carer responsibilities. Customisations to the program will result in modifying the app to include tracking of measures of interest, such as sleep quality, meal preparation, mood and confidence levels, smoking, alcohol consumption, social interaction, happy moments, time for self and a score for consumer mood. Records generated will be reviewed by social workers to help assess coping levels, quality of life and provide insights into early warning signs of potential adverse events which may prevent readmission of the consumer.

Evaluating the Platform

We will develop and test the technology with the same, or similar, group of stakeholders and then conduct a six month trial with ~20 carers in the Redcliffe Caboolture area. To evaluate the efficacy of the platform in improving ability to provide care, we will use retrospective assessment of hospital readmission and length of stay rates, as well as provision of service data entries on the mental health database CIMHA in the 12 months prior to trial of the platform technology.

Expected Outcomes

Outcomes from the consultative and development phase:

- Increasing carer participation in mental health hospital procedures and service delivery;
- Enhancing carer networks with mental health hospital and community services;
- Building confidence and capability in the stakeholder group that integrated and connected care is possible for this population
- Providing a process through which social workers can engage in research and innovation activities;
- Strengthening connections between mental health units, mental health services, community services and carers.

Once implemented, this technology has the potential to provide the following outcomes:

- Enhanced ability for carers to care for people with SMI due to increased information, support and services provided in a timely fashion.
- Shortened length of stay in hospitals as carers have an improved capacity for caregiving; and reduced readmissions due to preventing burn-out in carers.

- Enable social workers to apply evidence based social work interventions through better connections between MN Mental Health Service and carers and access a wealth of information on individual carer needs at any point in time.
- Utilisation across wider MN Mental Health services.
- An integrated role and partnership with community services that proactively responds to carers needs.

CONCLUSION

Providing carers with support, resource material and referrals to community services, delivered through a smartphone in the comfort of their home at times that suit them and their caring responsibilities will allow provision of the best possible care while managing their own stress and wellness levels. The platform provides integrated, connected care aimed at carers and has the potential to report on key performance indicators for mental health.

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