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Empowering Consumers to Take Charge is Key to Promoting Resilience, Independence and Self-Management

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Abstract

Purpose: The mental health sector has embraced the concept of consumer empowerment to ensure care and treatment is appropriate to meet their needs. Most progressive health services want to explore methods to implement processes to ensure consumers and their families participate in all aspects of health care planning, delivery and evaluation.

Methods: A narrative review of the literature was conducted to explore concepts that were relevant to develop the framework and method to promote resilience, independence and self-management.

Results: Irrespective of whether consumers are receiving care and treatment under compulsion or on a voluntary basis, empowering consumers with information at each stage of their assessment and management can enable them to take charge of their care and treatment.

Conclusions: Implementing PRISM (Promoting Resilience, Independence and Self Management) is facilitated by use of specific tools, protocols and methods to ensure mental health consumers can take charge of their own care and treatment. It has the potential to enable services to provide consistent, holistic and integrated care in an efficient and effective manner.

Keywords

Case management, Care coordination, Comprehensive care, Empowerment

Introduction

Use of compulsion for assessment and treatment of mental illness and mental disorder has been enshrined in legislation in various jurisdictions for the last two centuries [1]. Even though the criteria for compulsion varies across jurisdictions, commonalities include the presence of a mental illness or mental disorder, a risk of harm to self and/or others and exclusion of substance abuse, intellectual disability and some other conditions [2]. In most jurisdictions, the presence of risk in association with presence of a mental illness or mental disorder makes consideration of whether the person has the capacity to make decisions that are in their best interests almost redundant [3].

The exclusion of capacity to make decisions that are in a person's best interest is peculiar in relation to mental health matters as far as care and treatment decisions for a health condition are concerned [4]. It is also intriguing that once a compulsory order has been made, there seem to be requirements to engage, consult and co-produce a care and treatment plan for the consumer now under compulsory care. The only logical explanation can be that the element of societal control to manage risk is considered necessary despite the acknowledgement that majority of consumers with a mental disorder have the ability to take charge of their treatment [5]. When symptoms are severe and incapacitating, some people may not be able to take complete charge of all aspects of their functioning, however, as symptoms improve their ability to take charge of their functioning, care and treatment also improves [6,7].

Irrespective of whether a consumer is receiving treatment under compulsion or voluntarily, it is important that services have systems and processes in place to enable the mental health consumer to take charge of their treatment. A structured process of doing so with specific tools and methods can ensure the goal of promoting resilience, independent and

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self-management is achieved and mental health consumers receive consistent, comprehensive and appropriate care.

Provision of Comprehensive and Holistic Care

Most mental health consumers receive care, treatment and support in a community setting [8-10]. Inpatient stay, when it becomes necessary, is for a short duration to assertively treat symptoms that have increased in severity. For both treatment settings, emphasis must remain on symptom control to enable the individual to function to the best of their abilities, despite the mental disorder [11-13] and enable the consumer to function in personal, social and occupational spheres.

The mental health sector has embraced the concepts of recovery and rehabilitation with enthusiasm and re-framed the language to include to serve, care, assist, support, empower and enable [14]. This can be facilitated if consumers receive appropriate support to improve their resilience, independence and self-manage as many aspects as possible of their care and treatment.

PRISM

Promoting Resilience, Independence and Self-Management (PRISM) is a framework to enable mental health consumers taking treatment under compulsion or on a voluntary basis to take charge of decisions in relation to their own care and treatment. As is inherent within the concept of recovery, the PRISM framework endeavours to achieve for mental health consumers as much responsibility and independence in making decisions about their own care and treatment, as is possible for them to achieve.

Key PRISM Principle - I Must Manage My Own Care

The concept is driven from a simple starting point - `I must manage my own care.' If there are existing attitudinal, cultural, environmental or practice-related barriers that are likely to interfere with this aim, these are identified and systematically addressed. The emphasis is on developing of a shared organisational culture and clear understanding to enable the consumer to self-manage their care and treatment.

This is done through a three-pronged approach.

'Taking charge'

As soon as the mental health consumer is able to, they are encouraged to take charge of their care and treatment. This differs from the traditional case management model in which a case manager (and therefore the service provider) takes responsibility for the care provision to the consumer. In a traditional case management model, the service provider has the responsibility to ensure the consumer receives agreed interventions and to monitor processes to ascertain whether intended outcomes are being achieved.

In PRISM, the consumer is resourced and empowered to take charge. The consumer maintains a 'Take Charge Sheet' that lists all aspects of care that are expected to be completed (by the service providers and by them) and also specific time frames within which these need to be completed. If expected events and tasks are not completed, this is discussed with the mental health clinician at the very next clinical handover meeting.

PRISM requires every clinical handover to occur with the consumer. The Take Charge Sheet is the frame of reference to consider progress and whether target outcomes are being achieved. The Take Charge Sheet serves as a communication tool for discussion to occur about goals that need to be achieved. It is also a reminder of tasks that have to be completed and supports that the mental health consumer (and their carers) have access to.

Error-free care

PRISM requires the implementation of an agreed protocol for appropriate care (PAC) by the mental health service provider. The protocol details tasks that must be undertaken within a specified period. These include essential tasks that must be undertaken at the initiation of the contact with the consumer, at the point of comprehensive clinical assessment (including assessment of psychosocial needs and safety needs e.g. level of observation required in an inpatient setting and investigations that must be undertaken) and at the point of review of progress. The PAC sheet also separates tasks by responsibility for the mental health consumer and each member of the multidisciplinary team involved in the provision of care to the consumer. This ensures clear allocation of task responsibility as well the elimination of duplication and rework as all providers involved in supporting the consumer the consumer and their carers are clear about task allocation.

If there is deviation from the PAC, this is picked up instantaneously and remedied. If deviation cannot be corrected immediately, this is flagged with the nominated person and escalated if necessary, so that system correction can be implemented. At each clinical hand-over the Take Charge Sheet along with the PAC provide the basis for handover discussion.

Since PRISM endeavours to achieve error-free care, monitoring is in real-time and check for compliance is not left for a retrospective audit. Less than one hundred per cent compliance is considered unsatisfactory. With the consumer fully aware of actions on the `Take Charge Sheet' and within `PAC', at the clinical handover, the consumer participates in having deviations from PAC remedied straight away. There is immediate `exception reporting' for all matters that cannot be remedied.

Efficient coordination

In the process of care delivery, the most common reasons for any waste of time and effort are inefficient coordination and untidy communication. PRISM processes ensure that unnecessary transactions can be minimised. Since mental health consumers and mental health service providers are working from the same song-sheet there is an opportunity to explore and eliminate any duplication in documentation of information and all non-value-adding transactions. For exam-

ple, internal written referrals, staff clinical handover sheets, message boards, admission registers, communication sheets, ward rounds register; clinical review sheets etc. are all eliminated.

One consumer has one care plan and everyone involved must work from that plan. This is the plan that the consumer owns. It identifies needs, guides achievement of specific goals and intended outcomes, irrespective of the service provider and facility at which the consumer may be receiving care and treatment.

PRISM in Inpatient Settings

In the inpatient mental health setting, rolling out PRISM involves a number of structured steps.

Setting up phase

Systems and processes: During the set-up phase, an essential element of setting the system to enable the consumer to take charge of their own affairs is an environmental scan to identify any contributors that may be interfering with the service's ability to promote resilience, independence and self-management. For example, if there are activities that are done to, rather than completed with consumers, these are eliminated or modified. PRISM tools and methods are customised to meet the needs of the service ensuring that focus of care provision changes to self-management rather than a prescription of treatment. Inevitably some amount of system redesign becomes necessary. The service values and principles are aligned with principles espoused by PRISM. This allows clarity of purpose and direction for the service and removes any element of discordance that may arise with the introduction of a new service delivery strategy and method.

There is an explicit focus in PRISM to minimise waste and on ensuring all processes remain informative and value-adding. At every step, a question is asked whether activity or intervention is value adding. If not, that step is eliminated. Systems and processes for the consumer to take charge and manage their own care are supported by a back-end continuous evaluation process that tracks all activities and concurrently checks whether there is any deviance from agreed processes. Therefore, monitoring of the occurrence of errors and omissions is continuous. Unnecessary duplication in clinical care assessment and planning processes are eliminated, but essential assessment and treatment processes are monitored to ensure these are not overlooked.

Information for consumers and carers: A comprehensive information resource about services and supports available to consumers and carers customised for the service location is developed to ensure that consumers and carers have all the information they need to make care and treatment decisions. It is essential that this information is made available systematically and in a consistent manner so that consumers and carers feel fully equipped to take charge of their care and treatment.

Development of a customized `Take Charge Sheet' is the most important resource document so that it is ready for the consumer to take charge as soon as they are ready.

Implementation phase

The admission process is managed in a structured manner. In addition to completing a comprehensive mental health assessment, including assessment of clinical and psychosocial needs and identification of investigations needed, the mental health consumer is prepared well to manage their mental disorder and inpatient stay. This includes educating the mental health consumer about the concept of promoting resilience, independence and self-management using the PRISM Pack.

The PRISM Pack is not only an orientation and information pack available on the mental health consumer's bedside for ready reference, it is also an educational tool. The PRISM Pack makes explicit the Inpatient mental health service unit's commitment to enable the mental health consumer to self-manage. It also has information about resources available to the mental health consumers and clearly describes processes that are in place to promote self-management.

At the time of admission, many mental health consumers are not in a state of mind that allows them to fully understand the contents of the PRISM Pack. This requires the mental health staff to work with consumers and use the PRISM pack to continuously educate and orientate the consumer, as their treatment progresses.

The very fact that the mental health consumer and clinicians use the PRISM framework as a common frame of reference ensures that as the consumer progresses towards wellness, independence and to discharge from the hospital, they are progressively equipped with necessary information and skills to manage their own mental disorder. The PRISM pack conveys a simple message - "Take Note, Take Charge, Take Home".

Take note: This ensures that consumers and carers have access to relevant information about the service, service providers and supports available and that this information is available consistently. A Take Note information pack is available to all consumers and their carers all the time. The Take Note pack contains information developed in such a manner that it allows a discussion amongst all involved to enable consumers and carers to `take note' of the service's orientation to promote, resilience, independence and self-management, and about supports available for them.

Take charge: A Take charge sheet is a template that contains a clear and explicit statement inviting the consumer to take charge of their own recovery. The Take Charge sheet facilitates care processes to empower the consumer to take charge of their mental illness and treatment. At every stage of treatment, including at handovers, a Take Charge Sheet is used as an instrument to have a conversation with the consumer (and their carers, as appropriate) about how they can take charge of their treatment and recovery.

Take home: At every transition point, especially at the end of each contact with the service (for example, at the completion of an episode of admission), the Take Home sheet ensures that consumers (and their carers, as appropriate) are

absolutely clear about their care plan (and relapse prevention plan). Unless it is clinically inappropriate, the Take Home sheet includes the plan of care and details of treatment that consumers can take home.

PRISM in the Community

Most people with a mental disorder receive treatment in an inpatient unit for a short period of time. An inpatient stay enables effective management of risks, review of the treatment plan, re-stabilisation of mental state and re-establishment of a clear plan of treatment to enable the return of consumers to live in the community. Once discharged from the inpatient unit, with necessary support most consumers are able to manage their affairs, either by themselves or with the assistance of their carers.

The essence of recovery-orientated care is to ensure that consumers can achieve the highest level of functioning and make independent decisions. From achieving self-care to making independent decisions about what is in their own best interest, the focus of caring services must always be to support the consumers to take charge of their life to whatever extent possible.

A minority of consumers need considerable support and supervision, without which they are unable to maintain their optimal health and well-being. For this minority, considerations are not dissimilar to those people with other disorders of the brain and cognitive functioning who are incapable of making independent decisions e.g. people with dementia, mental retardation, brain injury, etc. Caring services must allow them to become as independent as possible.

For treatment in the community PRISM principles remains the same - to encourage all mental health consumers to self-manage as many aspects of their treatment as possible. The system orientation is to allow the consumer to take responsibility for self-managing aspects of care that they can. The PRISM pack conveys a simple message of "Take Note, Take Charge, Take Home".

The consumers and their carers are equipped with necessary information about supports available in the community (Take Note) to ensure they have access to appropriate resources in the community and encouraged to take charge of accomplishing tasks to enable them to manage their illness (Take Charge). For example, quite early on in their treatment, consumers are encouraged to take charge of the social aspect of their treatment. This includes facilitating them to manage communication with significant others and primary care practitioners. They are encouraged to ring healthcare professionals supporting them, including their General Practitioners to make an appointment for follow up. At their appointment with their General Practitioner, they are encouraged to suggest to the General Practitioner to arrange for their review to occur with the mental health team supporting them.

With the improvement in their mental state they are encouraged to take charge of recommended monitoring and evaluation processes that the treating clinician may have recommended; keep track of the fact whether investigations, including metabolic screening that may be included in their treatment plan, are being progressed promptly and even take charge of maintaining a record of some observations e.g. body weight, waist circumference, blood pressure, etc. All consumers are encouraged to formulate care plans in their own words so that it makes sense to them and use it for future reference (Take Home). This must always include identification of early warning signs of relapse and a relapse prevention plan.

For the majority of people with mental disorders who are able to live independent in the community, intrusive home visits, an insistence that consumers stay in contact by attending appointments, by telephone, etc., are in fact discouraged, unless the consumer feels the need to have this support and intervention. Follow up appointments with mental health and other support professionals, including acceptance of home visits must be an active decision-making process, not a passive acceptance of an offer made by the service provider.

The question that needs to be asked for this majority who are receiving treatment in the community and on the path of recovery is whether case management is necessary? Implementation of PRISM suggests that rather than case management, we must promote resilience, independence and self-management, to allow consumers to be truly independent. For people who can live independently, they should have a responsibility to `access' care, rather than service providers `providing' care. Health care access considerations for them should not be any different from those who have other chronic health conditions.

Conclusions

To do things differently, there is a need for all stakeholders to be sure that the new way of thinking and doing things is likely to deliver significant gains. The logical first step in this process must be a willingness to interrogate the concept and trial various elements of the concept. The promise of effective care, proposed efficiency gains and improvement in the environment must be tested to ensure that the theory can be translated into practice.

Adoption of PRISM challenges health care providers to question contradictions that are sometimes inherent in how care and treatment is delivered to mental health consumers. Even though the mental health sector is geared to encourage recovery and wishes to facilitate self-management, at times necessary systems and processes do not necessarily enable it to occur. PRISM allows the consumer to be empowered with the necessary tools and methods to self-manage and take charge of their own recovery.

To implement PRISM, it is important and necessary to customise the PRISM pack to meet local needs. Existing policies and procedures and documentation requirements require refreshment to ensure PRISM principles and practices are adhered to. The PRISM pack is built around the simple message of `Take Note, Take Charge, Take Home' with the intention of gathering necessary resources to empower consumers and their carers.

The PRISM pack allows necessary customisation to make it suitable and relevant for the local environment while pre-

serving essentials. For example, `Take Note' resources must always include an information guide that contains information about supports that are potentially available to consumers and cares, and how to access their supports. `Take Charge' sheet can be an eight to ten-point checklist of essential tasks that consumers must take charge of, that are critical for their ongoing treatment, recovery and rehabilitation. 'Take Home' sheet can be a template for a care and relapse prevention plan prepared and owned by the consumer that then becomes the point of reference for everyone involved in supporting the mental health consumer.

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