

Promoting Resilience, Independence and Self-Management in Palliative Care Settings



Dinesh K Arya*

Master Black Belt in Lean Six Sigma, Complete Health Solutions Pty Ltd, Australia

Submission: August 10, 2020; **Published:** August 19, 2020

***Corresponding author:** Dinesh K Arya, Master Black Belt in Lean Six Sigma, Complete Health Solutions Pty Ltd, Australia

Abstract

The concept of consumer empowerment to ensure health care and treatment is appropriate to meet their needs is widely embraced. Most progressive health services implement processes to ensure consumers and their families participate in all aspects of health care planning, delivery and evaluation. This paper provides a framework to promote resilience and independence of consumers in palliative care settings and describes processes services can introduce to encourage consumers to manage their own care and treatment. Implementing PRISM (Promoting Resilience, Independence and Self Management) is facilitated by use of specific tools, protocols and methods to ensure the palliative care consumer is able to take charge of their own care and treatment.

Keywords: Self management; Resilience; Independence promoting resilience; Independence and self-management in palliative care settings

Introduction

Recipients of palliative care have to navigate a number of challenges within a very short span of time. It is not only deterioration in their physical health but also the acceptance of the inevitable that life is coming to an end, can test resolve and identity of people who may have been resilient and independent for most of their life. Majority also have co-morbidities, some of which can interfere with their ability to function in personal, social and occupational spheres [1]. Indeed, an important goal of treatment, both pharmacological and non-pharmacological, must remain symptom control to enable the individual to function to the best of their abilities, despite their comorbidities [2-4].

Despite acknowledging the inevitability of death, most people receiving care in palliative care settings maintain hope and have the intention to make the most of available time [5]. Majority of palliative care consumers have the ability to take charge of their treatment. A number of self-management paradigms exist to support management of chronic medical diseases [6-9] and chronic palliative care disorders [10]. It is true when symptoms become severe and incapacitating, some may not be able to take complete charge of all aspects of their functioning, however, it is important that services have systems and processes in place to promote resilience and independence and ensure consumers in

palliative care settings are able to self-manage their comorbidities for as long as they are able to. Use of specific tools and methods can ensure the goal of promoting resilience, independent and self-management is achieved and palliative care consumers receive consistent, comprehensive and appropriate care, every time.

Provision of Comprehensive and Holistic Care

It is not uncommon that consumers who receive care in palliative care settings have to self-manage numerous symptoms including pain, dyspnea and vomiting as well as emotional issues in face of uncertainty about their prognosis and duration for which they may need to stay in a palliative care setting. The fact that majority of people are able to manage their symptoms and affairs until late into their illness, it is incumbent on palliative care providers to promote resilience and independence of consumers and enable them to self-manage as many aspects of their life and functioning, as is possible for them to do.

Every palliative care setting attracts some very caring, compassionate and committed professionals interested in devoting their life to support people at the time that is most uncertain and anxiety provoking. It is important that the palliative care sector embraces the concepts of empowerment and promoting self-management with enthusiasm and re-frame the

language to include empowerment and enablement. Uncertainty can be reduced by ensuring appropriate information [11] which enables consumer engagement in decision making [12].

PRISM

Promoting Resilience, Independence and Self-Management (PRISM) is a framework to enable palliative care consumers to take charge of decisions in relation to their care and treatment. This framework endeavours to achieve for consumers as much responsibility and independence in making decisions about their own care and treatment, as is possible for them to achieve. In introducing PRISM to promote resilience, independence and self-management, even though it is important to be cognisant of existing attitudes, culture, environment, practice and also systems and processes, the concept is driven from a simple starting point - 'I must manage my own care.' With implementation of systems, processes and practices that are an integral part of PRISM, emphasis is on developing of a shared culture and understanding to deliver care to palliative care consumers.

Preparatory Phase

PRISM has been conceived using lean six sigma principles [13]. There is an explicit focus on minimising waste and duplication of processes. Value adding activities are identified. At every step, a question is asked about value and only value adding activities are pursued. An automated backend evaluation process occurs concurrently by checking deviance from agreed processes to minimise any errors and omissions. There is focus on ensuring all consumers and carers receive appropriate and adequate information about supports available for them in a consistent manner so that they can take charge of their care and treatment. 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. During a treatment episode, as soon as the consumer is ready to take charge, this is formally identified and 'Take Charge Sheet' activated.

During the preparatory phase, attention is paid to the environmental contributors that may be interfering with the systems' ability to promote resilience, independence and self-management. PRISM tools and methods are then customised to ensure self-management is promoted. Inevitably some amount of system redesign is necessary to ensure PRISM processes are aligned with the vision and direction of the palliative care service provider. In implementing PRISM, the service provider also has an opportunity to review its own environment and if necessary, state, reiterate and/or align its principles of care delivery with the principles espoused by PRISM. This allows clarity of purpose and direction for the service and removes any element of discordance that may arrive with introduction of a new service delivery strategy and method.

It is not unusual for the service providers to be clear about what needs to be done, however, the principles driving care delivery are not clear to consumers and carers. PRISM processes ensure that agreed systems and processes are communicated and applied consistently.

Key Principles for PRISM

"I must manage my own care"

Three key components provide scaffolding to achieve this principle.

Taking Charge

For as long as the palliative care consumer is able to, they are encouraged to take charge of their care and treatment. This differs from the traditional case management in which a case manager (and therefore the service provider) takes responsibility for ensuring the consumer receives agreed interventions which form their care plan and also takes responsibility for monitoring process 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 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; a reminder of tasks that have to be completed; and supports that the palliative care consumer and carers have access to.

Error Free Care

PRISM requires implementation of an agreed protocol for appropriate care (PAC) by the palliative care service provider. The protocol details exact tasks that must be undertaken within a specified period of time. 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) and investigations that must be undertaken. The PAC sheet also separates tasks by responsibility for the palliative care 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 as elimination of duplication and re-work as all personnel involved 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 handover the Take Charge Sheet along with the PAC provide the basis for handover discussion.

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 percent 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 straightaway. There is no retrospective auditing as emphasis is on achieving one hundred percent compliance for tasks to be completed and immediate 'exception reporting' for all matters that cannot be remedied.

Efficient coordination

Most common reasons for waste of time and effort are inefficient coordination and untidy communication. PRISM processes have been developed to ensure unnecessary transactions can be minimised. Since palliative care consumers and palliative care 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 example, internal written referrals, staff clinical handover sheets, message boards, admission registers, communication sheets, ward rounds register, clinical review sheets etc. are all banned. 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 palliative care setting, rolling out PRISM involves a number of structured steps.

Preparatory Phase

The admission process is managed in a structured manner. In addition to completing comprehensive palliative care assessment, including assessment of clinical and psychosocial needs and identifying what investigations are needed, the palliative care consumer is prepared well to manage their comorbidities and stay in the palliative care accommodation. This requires educating the palliative care 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 palliative care consumer's bed side for ready reference, it is also an educational tool. The PRISM Pack makes explicit the inpatient palliative care service unit's commitment to enable the palliative care consumer to self-manage. It also has information about resources available to the palliative care

consumers and clearly describes processes that are in place to promote self-management.

Some palliative care consumers may not be in a state of mind that allows them to fully understand the contents of the PRISM Pack. This requires the palliative care 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 palliative care 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 palliative care facility, they are progressively equipped with necessary information and skills to manage their symptoms. The PRISM pack conveys a simple message – "Take Note, Take Charge, Take Home"

Take note: To ensure the consumers and carers have access to relevant information about the service, service providers and supports available and information is made available consistently, a Take Note information pack is available to all consumers and their carers. The Take Note pack has information developed in such a way that allows a discussion amongst all involved to enable the 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 symptoms, 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 (whether it is an episode of admission or an appointment in the community), a Take Home sheet ensures that consumers (and their carers, as appropriate) are absolutely clear about their care plan. Unless it is clinically appropriate, the Take Home sheet includes plan of care and details of treatment that consumers can take home.

PRISM in the Community

Most people with palliative care needs receive treatment in the community. Most consumers, with necessary support are able to manage their affairs, either by themselves or with the assistance of others. The essence of recovery orientated care is to ensure that consumers are able to achieve the highest level of functioning including management of their day to day functioning, and making 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 brain and cognitive functioning who are incapable to 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 the majority of people with palliative care needs who are able live independent in the community, intrusive home visits, 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 palliative care 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 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 be able 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.

PRISM principles encourage all palliative care 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 are able to. The PRISM pack is used to convey 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, from the very beginning of 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 palliative care team supporting them.

With improvement in their symptoms 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 in a timely manner; 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 a care plan is something that makes sense to them and use for future reference (Take Home). This must always include identification of early warning signs of relapse and a relapse prevention plan.

Conclusion

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 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 sometime inherent in how care and treatment is delivered to palliative care consumers. Even though the palliative care sector is geared to encourage empowerment 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 preserving essentials. For example, 'Take Note' resources must always include an information guide that contains information about supports that are potentially available to consumers and carers, and how to access their supports. 'Take Charge' sheet can be an eight to ten-point check list 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 palliative care consumer.

References

1. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, et al. (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284(19): 2476-2482.

- Goldberg SB, Tucker RP, Greene PA, Davidson RJ, Wampold BE, et al. (2018) Mindfulness-based interventions for psychiatric disorders: A systematic review and meta-analysis. *Clin Psychol Rev* 59: 52-60.
- Kim EJ, Bahk Y-C, Oh H, Lee W-H, Lee J-S, et al. (2018) Current Status of Cognitive Remediation for Psychiatric Disorders: A Review. *Front Psychiatry* 9: 461.
- Schatzberg AF, DeBattista C (2015) *Manual of Clinical Psychopharmacology*. In: (8th edn), Americal Psychiatric Publishing, Washington DC, USA.
- Bailey DE, Steinhauer K, Hendrix C, Tulsy JA (2011) Pairing Self-Management with Palliative Care: Intervening in Life-Limiting Illness. *J Nurs Healthc Chronic Illn* 3(1): 1-3.
- Lorig KR, Sobel DS, Stewart AL, Brown BWJ, Bandura A, et al. (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 37(1): 5-14.
- Newman S, Steed L, Mulligan K (2004) Self-management interventions for chronic illness. *Lancet* 364(9444): 1523-1537.
- Coleman MT, Newton KS (2005) Supporting self-management in patients with chronic illness. *Am Fam Physician* 72(8): 1503-1510.
- Kosmala-Anderson JP, Wallace LM, Turner A (2010) Confidence matters: a self determination theory of factors determining engagement in self management practices of UK clinicians. *Psychol Health Med* 15(4): 478-491.
- Arya DK (2012) PRISM: Promoting Resilience, Independence and Self Management--a strategy to manage chronic mental illnesses. *Asian J Psychiatr* 6(4): 303-307.
- Rooks RN, Wiltshire JC, Elder K, BeLue R, Gary LC, et al. (2012) Health information seeking and use outside of the medical encounter: is it associated with race and ethnicity? *Soc Sci Med Soc* 74(2): 176-184.
- Moore DG, Green JS, Godlis HA (2009) Achieving desired results and improved outcomes: integrating planning and assessment throughout learning activities. *J Cont Educ Health Prof* 29(1): 1-15.
- Carrigan MD, Kujawa D (2006) Six sigma in health care management and strategy. *The Health Care Manager* 25: 133-141.



This work is licensed under Creative Commons Attribution 4.0 License
DOI: [10.19080/PMCIJ.2020.03.555621](https://doi.org/10.19080/PMCIJ.2020.03.555621)

Your next submission with Juniper Publishers will reach you the below assets

- Quality Editorial service
- Swift Peer Review
- Reprints availability
- E-prints Service
- Manuscript Podcast for convenient understanding
- Global attainment for your research
- Manuscript accessibility in different formats
(Pdf, E-pub, Full Text, Audio)
- Unceasing customer service

Track the below URL for one-step submission
<https://juniperpublishers.com/online-submission.php>