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Patient and caregiver needs; is it important to separate them during the palliative care consultation clinic? – Findings from the pilot of an initial new client psychosocial assessment clinic.

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Palliative care service provision is being influenced by a changing policy, delivery and funding framework. Services need to address these frameworks in their approaches to care delivery and planning. This report describes the rationale for and assessment of an innovative assessment clinic for community outpatients in a South Australian palliative care service. Three core drivers for change were identified:

- South Australia released its Statewide Services Plan - Palliative Care in 2009 with an emphasis on
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(SA Health, 2009 p.9).
- Across Australia specialist palliative care services (SPCS) are encouraged to participate in a process of self-assessment against the 13 palliative care standards through the National Standards Assessment Program (NSAP), (Palliative Care Australia, 2012). Psychosocial needs of patients and their caregivers are highlighted in many of the standards with an expectation that there are processes in place to ensure that assessment of these needs occur routinely. The NSAP process of self-assessment enables the SPCS to review its current model of care and provides an opportunity to test new and innovative ways of meeting needs identified through the quality improvement cycle of Plan Do Study Act (PDSA). For this South Australian SPCS, self-assessment identified that the focus of care was directed predominantly towards the findings from physical symptoms of the patient; information provision was depending on where patients enter the service; and caregivers were not routinely assessed.

- Commonwealth Government funding through a programme to support subacute care provision enabled the appointment of a community social worker, caregiver network facilitator, and nurse practitioner candidate. New and emerging roles such as the Caregiver Network Facilitator had been identified within the Statewide Palliative Care Plan as a way to actively support the informal family caregiver maintain a loved one at home. (SA Health, 2009). The strength of this role lies within a dedicated staff member assisting the family caregiver to identify their own social and informal supports thus building social capital and strengthening community capacity. (Greene et al, 2011).

New team members, findings from the NSAP self-assessment and directions for care outlined in the Statewide Plan challenged the existing team to review the way in which they work. This planning and review process led to a decision to pilot an initial assessment psychosocial clinic based in a community setting. One of the objectives of this clinic is to offer early assessment and screening to meet the early introduction to palliative care identified as best practice by the World Health Organization. This is also supported strongly through Palliative Care Australia with the National Palliative Care Standards emphasizing the need for an interdisciplinary assessment of both the patient and caregiver. Central to the structure of this clinic is the capacity to engage with the patient and the carer separately as well as together to provide the clients with the opportunity to raise concerns that may not be raised when seeing the patient and carer together.

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A preliminary review of the literature was conducted using the databases of, PubMed, CINAHL and CareSearch (Tieman et al, 2005). The purpose of the review was to identify possible structures for the clinic, tools for use in assessment, and needs of community patients and their caregivers. The

search words included psychosocial clinic in palliative care, psychosocial care in palliative care, caregivers in palliative care, ambulatory care and quality of life in palliative care.

The literature review showed that patients and caregivers have multiple and diverse information and supportive needs. Kirk, Kirk and Kristjanson (2004) explored information needs of patients with cancer and their family members. Of note was that information needs changed as the illness progressed. Often patients chose to know less the sicker they became with families needing to know more as the patient neared the terminal phase. The areas identified as requiring the most information included pain management, fatigue, and home care resources. Unanswered questions contribute negatively to the patient's ability to cope with their illness and caregivers feel there is a negative impact on their ability to care for the patient. (Selman, L. Higginson, I. Aguiro, G. et al, 2009)

Miller and Walsh (1991) introduced the palliative care social work assessment tool for patients with advanced cancer which was completed concurrently during an initial interdisciplinary consultation. The overall findings identified that most patients simultaneously experience multiple physical symptoms, emotional distress, home management concerns, financial difficulties and family fatigue. The Bakitas study which holds significance within the palliative care community as being the first randomized controlled study to show an improvement in Quality of Life through timely provision of education and information. (Bakitas et al, 2009).

Studies showed that supportive care can be overlooked and that multidisciplinary assessment may improve satisfaction and decrease symptom distress (Pituskin E, Fairchild A, Dutka J et al 2010). Harrison and Watson's reported on a partnership model between specialist palliative care and chronic renal disease providing symptom management, empowering patients to make their own choices and supporting them with advance care planning (2011).

A number of studies looked at the use of screening tools within an ambulatory clinic to better identify the psychosocial needs of not just the patient but of significant family members as well. The FAMCARE -6 tool was evaluated within an oncology outpatient clinic suggesting it is suitable as a screening system for psychological care of oncology patients (Carter, Lewin, Gianacas et al, 2011) while Payne, Barry, Creedon et al's 2007 study, indicated that a two question screening tool for depression could be meaningfully used in screening for depression in palliative care patients.

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Informed by the literature review, findings from the NSAP self-assessment and input from the clinical staff, the structure of the clinic was finalised. In setting up the clinic the clinicians came together to break down the assessment elements and identify where they were best located and with whom. Informed by the literature review, findings from the NSAP self-assessment and input from the clinical staff, the structure of the clinic was finalised. The focus of this clinic is on patients who are referred early to palliative care. Screening is conducted across the physical, social and emotional domains of the patient and caregiver illness experience. The clinic has been structured to address the physical concerns first, so the patient and caregiver start with the Nurse Practitioner. Together they then move onto the social worker to explore practical issues such as Advance Care Planning as this is often not addressed until late in the illness journey (Silvester et al, 2012). The patient and his/her caregiver are then separated to provide them privacy to discuss the illness experience for the patient and the caregiving experience for the caregiver. This approach of separating the patient and caregiver is the focus of this pilot study.

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The team utilized the Needs Assessment Tool: Progressive Disease – Cancer (NAT:PD-C). This validated tool is designed to assist referrers to palliative care to determine if the need requires support of a specialist service. It is also there to support specialist palliative care services to determine if the needs of the patient require ongoing support from the program. (Waller et al, 2010)

Ethics approval was obtained from The Southern Adelaide Clinical Human Research Ethics Committee (Application number 462.11, December 2011). Patient and caregiver satisfaction surveys were developed based on existing tools from the Palliative Care Outcomes Collaborative (Eagar et al, 2010), and the National Standards Assessment Program, with accompanying information sheets regarding how to complete them.

The clinic commenced in September 2011 and every patient and caregiver was asked if they would be happy to participate in the evaluation once ethics approval was granted. These questionnaires with a focus on acceptability of the clinic were posted out with a reply paid envelope to all who attended the clinic from September 2011 to March 2012. Patients and their caregivers were sent the questionnaires separately.

The questionnaire was constructed to reflect the flow of the clinic, and was set out as a satisfaction tool using a scale from 0-10, where 0 reflects extreme dissatisfaction and 10 reflects extreme satisfaction. The tool commenced with general demographic details, and then specific questions related to the community health environment, location of clinic and ease of access. It then moved into the clinician aspect starting with the Nurse Practitioner, and then the Social Worker, and then patients were asked to comment on their session with the Psycho-Oncology Nurse, and caregivers to comment on their session with the Caregiver Network Facilitator.

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From the clinician perspective, the clinic provides a thorough assessment and triages the level of need of the client; in some cases this assessment has identified that there is no pressing need at the time of assessment and returns the client back to their primary care provider for ongoing management with recommendations and suggestions if problems arise in the future. The clinic approach assists in identifying needs at referral and ensuring resources are being accessed

appropriately. The referrals that result from this clinic include palliative medicine assessment, formal psychiatric assessment, referrals for complementary care services, access to volunteers and early introduction to the community nurse if that is required.

Details on the number of clinic attendees and survey response rates are summarised in Table 1.

	Patients	Carers	Total
Attended	41	37	78
Patient response / no caregiver response	6		6
Carer response / no patient response		4	4
Matched Patient and carer response	12	12	24
Bereaved		2	2
Response rate	44%	49%	46%

The overall satisfaction of the clinic is rated highly by both patients and caregivers. The dyad responses identify that patients and caregivers can experience information quite differently despite sitting in the same interview. Often the patient felt less prepared by the service of what to expect from the clinic, compared to their caregiver. A recurring comment was the difficulty in locating the community health building and parking. The building had only been open for a few weeks when services were commenced there. Some of the fine tuning subsequently has required precise details in the information that is sent out to clients prior to attending the clinic which has resulted in verbal reports of improved satisfaction with clients accessing the clinic.

The opportunity for time with the community social worker proved valuable for clients and caregivers who often attend this clinic with many unanswered questions and a great need for information. The issues regarding financial support, access to superannuation, preparing a Will and

thinking about Advance Care Planning are practical aspects that clients appreciate receiving information on.

One patient stated that meeting the social worker [REDACTED] The patient then went on to say “ [REDACTED]

The point of difference with this clinic is the separation of client and caregiver after they have undergone the physical and social work assessments. Patients are screened for any prior mental health history and their overall ability to cope and adjust to the challenges of a life limiting illness, while their caregiver is assessed for their willingness to care and ability to cope and manage the role of caregiving. While 94% of patients had no problem with being separated from their caregiver for this session, a smaller percentage (83%) of caregivers had no issues. The caregivers did not provide any comment within the questionnaire as to why they had not liked being separated from the patient. Those caregivers that provided comments regarding time away from the patient talked only of the positive benefits.

@ [REDACTED]
(caregiver14B)

@ [REDACTED]
[REDACTED]

Caregiver 30B stated that she benefitted from privacy as her husband is [REDACTED]

@ [REDACTED] @ [REDACTED] @ [REDACTED]
[REDACTED]

Comments from the patients identified the opportunity for privacy enabled them to explore feelings without having to protect their caregiver from their emotional reaction.

Patient 1A stated that having time alone as a caregiver was beneficial stating "I was able to express my feelings to the doctor and the nurse and they were able to help me understand what was going on with my loved one."

Patient 23A found the discussion of the impact of illness on quality of life to be beneficial stating "I was able to talk to the doctor and the nurse about my loved one's quality of life and they were able to help me understand what was going on with my loved one."

Eighty percent of patients and caregivers felt that the opportunity for privacy enabled significant conversations to take place outside of the clinic with family members. The issue of where patients want their end of life care to be provided, while confronting for many of them was identified to be helpful in their planning for the future.

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The results suggest that the clinic structure offers patients and their caregiver's privacy to explore their own feelings in regard to the way they are coping and adjusting to living with a life limiting illness. It provides a mechanism for different information and supportive needs to be addressed which may not have been raised in the traditional clinic format.

When the clinicians reconciled their assessments at the end of the clinic, there were often comments that individual staff have to learn to accept that they are not the collector of all the information and that they have to trust that their colleagues will fill in the information gaps that they may have sought out had they undertaken a solo assessment. Clinicians providing this service have reported that they appreciate the interdisciplinary assessment process and that the debrief at the end of clinic supports their decision making regarding identification of risk factors, areas of high

priority that need to be taken back to the wider team, or their decision to refer the patient back to their General Practitioner as the needs do not warrant specialist involvement at this time.

As a result of this pilot future evaluation of the clinic is underway. This work is exploring through a mixed methods communication study:

- Whether the emotional content between the patient and caregiver interactions differ when seen separately as opposed to together.
- The role of the caregiver when present in a clinic setting and how they contribute within the consultation
- Communication styles of the various clinicians when discussing end-of-life issues.

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This study was implemented to test acceptability of a new clinic model within the service. Never before has this service deliberately separated patients from their caregivers in the clinic setting. A satisfaction questionnaire was used; however greater value was obtained from the free text comment boxes. A qualitative study using focus groups and semi structured interviews of past participants would have been helpful to better understand the experience of the clinic for attendees. The addition of clinician feedback would also be helpful both from the perspective of the external referrers and the internal palliative care team members

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A new model of clinic assessment was introduced as a response to changing health system priorities and issues identified in a self-assessment study undertaken by the palliative care service. The format of the new clinic was informed by a literature review and feedback and input from the clinical team. The new clinic provides the opportunity for a comprehensive combined and individual assessment of

the patient and the carer. Data from the initial evaluation shows that is well received by attendees and offers the opportunity to raise and address issues which may not have been addressed in more traditional clinic formats.

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