



# The Parent Support Worker: Impact of a Novel Cross-Sector Service for Parents with Cancer and their Adolescents and Young Adult Children

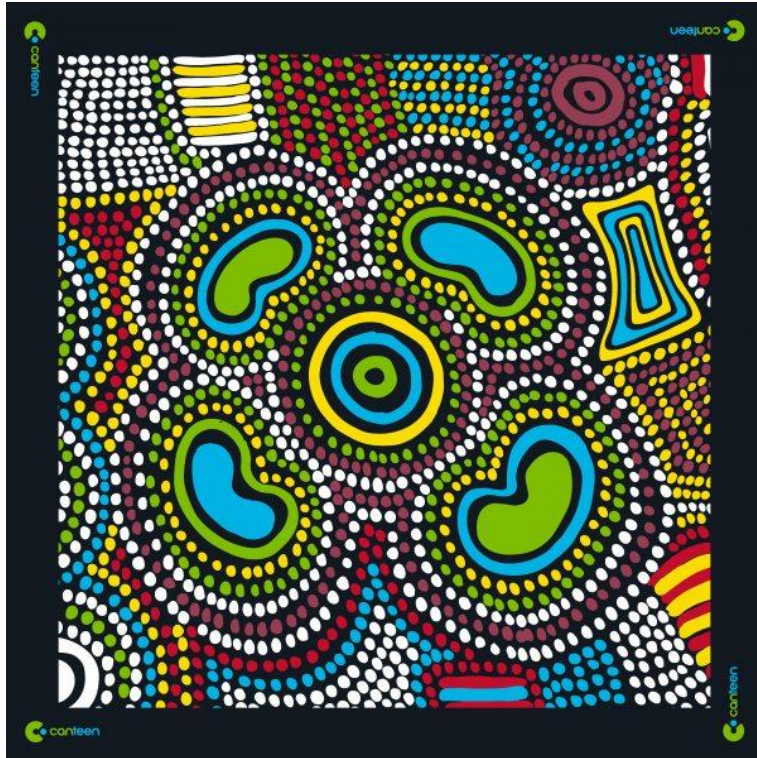
20 min Oral Presentation

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# Acknowledgement of Country



I'd like to begin by acknowledging the Jagera people and the Turrbal people as the Traditional Owners of the land on which I'm presenting from today Meanjin (Brisbane), and pay respect to elders past, present and emerging. I acknowledge and respect the Meanjin people's cultural, spiritual, physical and emotional connection to their land, waters and community.





# Overview

A woman with long hair is holding a young child in her arms. They are standing in a park-like setting with trees in the background. The sun is low in the sky, creating a strong lens flare and a warm, golden light that silhouettes the woman and child. The overall mood is peaceful and intimate.

Confidence in parenting abilities decreases after a cancer diagnosis

Interventions have not been routinely implemented in healthcare

Family of adult cancer patients miss out on psychosocial support (including children)

Professional support is needed but not embedded in standard practices

Communication with children about cancer is parents' greatest concern

The coordination and integration of the health sector and community-based organizations is key to improve the quality of healthcare

# The Parent Support Worker Role



A novel cross-sector model of care to assist families with Adolescent and Young Adult (AYA) where a parent has cancer



Dedicated social workers (parent support workers; PSWs)



Systematic identification of parent patients with AYA children



Psycho-education, communication strategies, practical support, and referrals of AYA children to community-based support



The new model of care was piloted in three Australian hospitals



# Objectives

The background of the slide features a warm, orange-toned sunset or sunrise sky. In the foreground, the silhouettes of four people are visible, standing and holding hands in a line, facing away from the camera towards the horizon. The overall mood is hopeful and supportive.

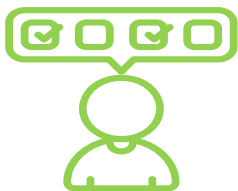
To evaluate the **effectiveness** of the PSW service in **improving parenting and psychosocial outcomes** in parents with cancer

To explore parents' **satisfaction** with the PSW service

To identify the impact of the PSW service on **referrals of young people** with a parent with cancer **to community services**

# Methods

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## Pre and Post Session Surveys

Measures of parenting and psychosocial outcomes

Demographics and cancer information

Satisfaction



## Satisfaction Survey

Parents who did not complete pre and post session surveys

Demographics and cancer information

Satisfaction



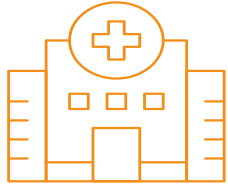
## AYA Referrals to Community Support

Data collected by a community-based organization

Number of AYA referrals from the three hospitals



## Hospital 1



Victoria

Hospital  
dedicated to  
oncology care

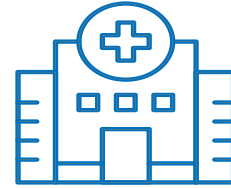
## Hospital 2



New South Wales

General hospital  
without a specific  
cancer ward

## Hospital 3



New South Wales

General hospital  
with an integrated  
cancer center

# Pre-Post Session Survey



N=36 **92%** Female



age

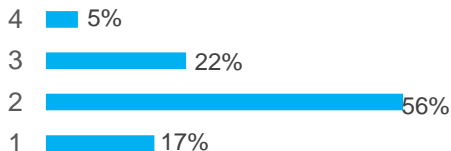
Mean age= 41.2 years  
(30-56 years old)

**19%**

Spoke a language different  
from English at home



Number of  
children



**86%**

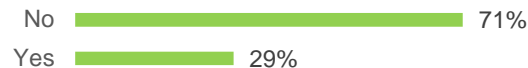
Lived with partner

**56%**

Had to seek alternative  
childcare support



Previous mental  
health services



**100%**

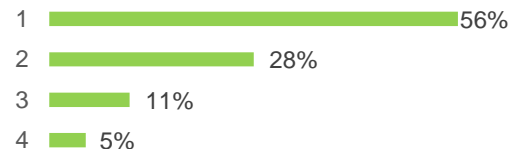
Cancer patients

**97%**

First cancer diagnosis



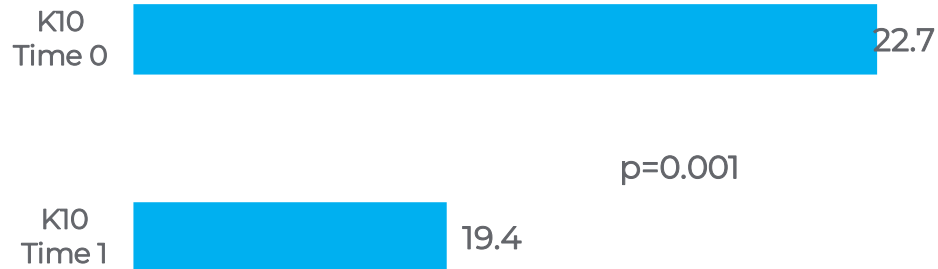
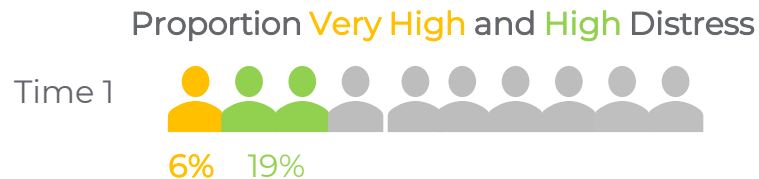
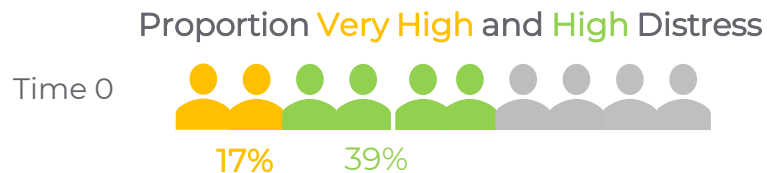
Number of  
sessions





# Distress (K10)

K10 Scores **Very High (30-50)** and **High (22-29)**



# Parental Efficacy in Helping and Supporting their Children (CASE)

CASE Time 0



47.7

p= 0.001

CASE Time 1



62.8

	Not at all confident					Very confident				
1. I am able to maintain close communication with my child(ren) about the cancer	1	2	3	4	5	6	7	8	9	10
2. I have what it takes to help my child express fears or worries about the cancer.	1	2	3	4	5	6	7	8	9	10
3. I have what it takes to help my child fully discuss what's bothering him/her about the cancer.	1	2	3	4	5	6	7	8	9	10
4. I am able to help draw out my child's issues related to the cancer.	1	2	3	4	5	6	7	8	9	10
5. I can assist my child to talk out their worries about the cancer.	1	2	3	4	5	6	7	8	9	10
6. I have what it takes to help my child add to his/her ways of coping with the cancer.	1	2	3	4	5	6	7	8	9	10
7. I can help add to my child's skills to manage what's happening because of the cancer.	1	2	3	4	5	6	7	8	9	10
8. I have the skills to decrease my child's level of distress related to the cancer	1	2	3	4	5	6	7	8	9	10
9. I know what it takes to add to my child's comfort level related to the cancer.	1	2	3	4	5	6	7	8	9	10



# Parenting Concerns (PCQ)

PCQ Time 0



2.9

$p=0.001$

PCQ Time 1



2.3

For each line, how <b>concerned</b> are you?	Not at all concerned					Very concerned
Factor 1: practical impact of illness on child	T0-T1(3.6-2.8) $p= 0.001$					
My own mood, worries or emotions are affecting my children	1	2	3	4	5	
My physical limits or low energy are affecting my children	1	2	3	4	5	
I am not able to spend as much time with my children as I would like	1	2	3	4	5	
The illness is changing my children's routine	1	2	3	4	5	
Changes in my memory or attention are affecting my children	1	2	3	4	5	
Factor 2: emotional impact of illness on child	T0-T1(2.8-2.3) $p= 0.001$					
My children are emotionally upset by the illness	1	2	3	4	5	
My children are worried that I am (or my partner is) going to die	1	2	3	4	5	
My children get upset when we talk about the illness	1	2	3	4	5	
My children might be in need of professional health care	1	2	3	4	5	
My children get confused or upset by what others say about the illness	1	2	3	4	5	
Factor 3: concerns about co-parent (To be complete)	T0-T1(2.1-1.8) $p= 0.026$					
My children's other parent would not be able to meet their emotional needs if I am unable to	1	2	3	4	5	
There is no one to take good care of my children if I am unable to	1	2	3	4	5	
My partner is not providing me with enough practical support	1	2	3	4	5	
My partner is not providing me with enough emotional support	1	2	3	4	5	
My children's other parent would not be a responsible caregiver if I were unavailable	1	2	3	4	5	



# Parent's Concerns (PV9)

For *Situation 1*, On average, over the last 2 weeks (please circle a number for each question):

	Not at all stressed/ bothered		Moderately stressed/ bothered			Extremely stressed/ bothered	
b. How much has it bothered or stressed you? (please circle a number)	1	2	3	4	5	6	7

Time 0 Bothered/Stressed  5.6

Time 1 Bothered/Stressed  3.9

$p=0.005$

Has *Situation 1* changed since talking to the Parent Support Worker?

It has got better

73%

It has got worse/  
hasn't changed

27%



# Satisfaction Survey



N=43

Hospital 1 12

Hospital 2 13

Hospital 3 18

61%

Female



49% 46-55 years

age



Number  
of children

5 5%

4 12

3 17

2 54

1 12

59% Patients

41% Partners



1-10 sessions (mean= 2.6)

8%

Spoke a language different  
from English at home



# Satisfaction with the PSW Service

88%

...reported that the  
PSW helped them a  
lot

93%


...felt much more  
confident or a little  
more confident with  
parenting through  
cancer

93%

...were very satisfied  
with the service







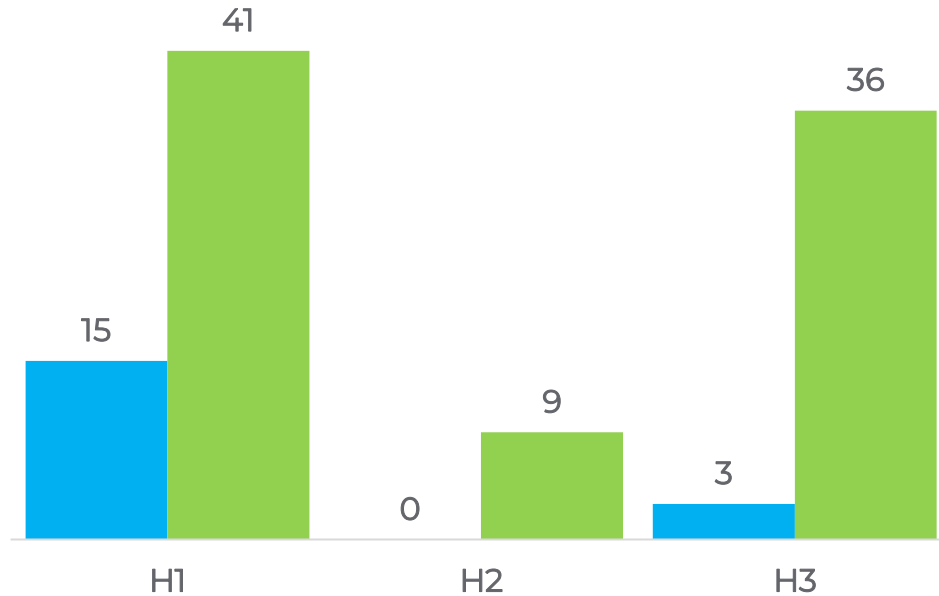
“This service has helped the family to cope & accept changes emotionally”  
(male, partner of cancer patient, 1 child)

“Pretty happy so far, but maybe email reminders in the future to follow up”  
(female, patient, 2 children)

“[The PSW] offered practical suggestions on how to tell my kids I have cancer. She was positive and supportive about how I was going to continue supporting my kids” (female, cancer patient, mother of 3 children)

“I would suggest a regular touch base phone call or meeting may help some people as not everyone will ask for assistance however are happy to open up and accept help when it is directly offered to them” (male, patient, 2 children)

# Referrals of AYA to Community Support



9 Months Prior to the  
Implementation of the PSW role

Last 9 Months During PSW role



# Discussion



## Findings

Significant improvement in parents' psychological distress and parenting outcomes

High satisfaction with the PSW service

Increased access for AYA offspring to community services



## Limitations

Small sample size for the pre-post survey

No representation of Aboriginal/Torres Strait Islander population

No control group



## Future Studies

Bigger samples

Purposively recruit parents from culturally diverse backgrounds

Purposively recruit partners of cancer patients



# Clinical Implications



This novel model of care improved psychological and parenting outcomes in parents with cancer

The model helped to fill a healthcare gap



Findings demonstrate the need for integrated care in supporting families impacted by cancer

# Thank You!



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