



Wig Service Evaluation Report

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Cancer Information and Support Service, Cancer Council Victoria

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ETHICAL APPROVAL

This project has been reviewed and approved by Cancer Council Victoria's Institutional Research Review Committee (Project No. IER 1601)

EXECUTIVE SUMMARY

Since November 2012, Cancer Council Victoria has offered a wig service for people experiencing hair loss as a result of their cancer treatment. Wig appointments are carried out by experienced cancer nurses at Cancer Council Victoria's office, located at 615 St Kilda Road Melbourne. The wigs are supplied free of charge to the wig service users. The service is supported by charitable donations.

Several Cancer Councils and other health services in Australia also operate wig services. Prior to this study, none of the wig services in Australia have been formally evaluated.

For Phase 1 of this study, a retrospective audit was conducted of the electronic nursing notes for the 654 people who had used the Cancer Council Victoria Wig Service between November 2012 and August 2015. A sub-analysis was conducted on the topics that were discussed by nurses with wig service users in their appointments.

In 2013, its first full year of operation, the Cancer Council Victoria Wig Service had an average of 18.8 appointments per month. The service has continued to gradually expand; with the average number of appointments per month in 2015 was 22.3.

At the time of this study, the Wig Service operated from a single location in St Kilda Road, Melbourne, despite 9.5% of users identifying as coming from rural and regional postcodes.

Sub-analysis showed that 65.2% of service users discussed one or more topics other than wigs or hair-loss with the nurse conducting their appointment. These topics that were documented as having been discussed in the Phase 1 data were analysed into four themes:

- Treatment
- Psychological / Emotional Support
- Referrals and Patient Navigation
- Other Miscellaneous Topics

Of the 138 people included in the sub-analysis, 64 discussed a treatment related theme with their nurse and 31 discussed topics related to emotional / psychological support.

Following the retrospective audit we conducted semi-structured interviews with 15 people who had recently used the Wig Service. From these semi-structured interviews five overarching themes were identified:

- Booking, travel to and arrival at the wig appointment
- Experience and satisfaction with the wig appointment
- Treatment and support discussed in the wig appointment
- Satisfaction with the wig
- Experience of hair-loss and the value of the Wig Service.

Fourteen of the 15 people interviewed expressed a high degree of satisfaction with the Wig Service and the nurses who conducted the wig appointments.

A third of wig service users who were interviewed were not sure when asked that the Cancer Council Victoria staff member conducting the appointment was a nurse. A third of

those interviewed also reported that they felt that there was some kind of a barrier to them discussing topics other than the wig and hair-loss during the appointment. These barriers included the perception that there was only a short amount of time to complete the appointment and not wanting to upset other family members who were present. Only one service users said that she had a topic she wished to discuss but did not get a chance. Another participant said that she felt like she was given more information and support than she needed.

Interviewees expressed a high degree of satisfaction with the wig they received from the Wig Service and reported using the wigs they had received frequently. The exception to this were two interviewees from culturally and linguistically diverse backgrounds who found it difficult to find appropriate wigs when they attended their appointment.

Other themes that came from the interviews with service users included:

- Wanting the wig so they would not be that center of attention
- Not wanting to confront or distress loved ones with their hair loss
- The ways the wigs they received from the Cancer Council Victoria wig service changed the way people felt about themselves
- Financial difficulties caused by prolonged cancer treatment making it difficult to afford to buy a wig
- Needing wigs to be able to feel comfortable at work.

Recommendations

1. That Cancer Council Victoria continues to offer the Wig Service in its current free nurse-led form and take steps to promote the positive impact of the service to donors to ensure the ongoing viability of the service.
2. To examine options to expand the Wig Service or increase the accessibility of the service for people experiencing cancer related hair-loss in rural areas and people who live in Melbourne but have limited access to transport.
3. Introduce a standardised introduction for service users for when they first arrive at the appointment so they are:
 - aware that it is an experienced cancer nurse who will conduct their appointment
 - aware of the length of the appointment so they do not feel a perceived time pressure when choosing their wig or discussing issues with the nurse
 - Informed of the range of services that they can access and ensure service users get the full benefit of their interaction with the service.
4. Look into offering a wider range of colors and styles of wigs to better cater for the users from culturally and linguistically diverse backgrounds.
5. As this is the first formal evaluation of a wig service of this kind in Australia, it is recommended that the results be disseminated to Cancer Councils in other states and other organisations with an interest in the psychosocial care of cancer patients who may be interesting in establishing a wig service in the future.

BACKGROUND

Hair-loss has long been established as a distressing side effect of cancer treatment¹⁻³. Patients can find the process of losing their hair during cancer treatment traumatising and their altered appearance can leave them feeling stigmatised^{1,3}. Cancer related hair-loss is associated with reduced quality of life, low self-esteem, depression and anxiety and it can have an adverse effect on patients' relationships and the likelihood of social interactions^{3,4}. Cancer patients who use wigs have reported a restored sense of self, increased self-confidence and increased social acceptance⁴.

Since November 2012, Cancer Council Victoria has offered a wig service for people experiencing hair loss as a result of their cancer treatment. Cancer patients who are experiencing hair loss can make a booking to be fitted for a wig at Cancer Council Victoria's designated Wig Service, located at 615 St Kilda Road, Melbourne. One hour is allowed for each wig booking, with appointments typically running between 45 minutes to one hour. Wig appointments are carried out by experienced cancer nurses who staff the Cancer Council 131120 Cancer Information and Support line. Wigs are supplied free of charge to service users and the Wig Service is supported by charitable donations. Wig service users also receive a follow-up phone call from a nurse approximately six weeks after their visit.

Several Cancer Councils and other health services in Australia operate wig services that aim to alleviate the distress experienced by those affected by cancer related hair-loss. Cancer Councils services in Queensland, the Australian Capital Territory, Tasmania and Western Australia have in-house wig services and use client satisfaction as a measure for service evaluation, however these forms are completed voluntarily, and to date have not been formally analysed. Cancer Council New South Wales and Cancer Council South Australia do not have in-house wig services. Prior to our study, neither Cancer Council nor external wig services in Australia have been formally evaluated.

AIMS

This study aims to describe the population of patients who have used the Cancer Council Victoria Wig Service and examines the satisfaction of the wig service users. It further investigates barriers to services use and provides a picture of the interaction between service users and the nurses who conduct appointments. These findings will:

- Inform our understanding of patients' experience of cancer-related hair loss
- Inform service improvement and development opportunities
- To provide a model for future evaluations of similar services.

METHOD

The study was carried out by students from the Masters of Nursing Science program at the University of Melbourne, under the guidance and coordination of Cancer Council Victoria staff. The study had two phases. The first phase was a retrospective audit of records from the Cancer Council Victoria Customer Relationship Management (CRM) system (a Salesforce database). The second phase comprised a series of semi-structured phone interviews with service users to further explore a number of themes that emerged from the Phase 1 data.

Retrospective audit

A series of CRM reports were run to extract data that had been collected on the 654 people who had used the Cancer Council Victoria Wig Service between November 2012 and August 2015. Data fields which could potentially be used to identify patients (name, address, phone numbers) were excluded from reports so all data was produced in a de-identified form. The reports were designed to capture the following information from each service user's record:

- Contact ID (unique CCV database identifier)
- Postcode
- Age
- Country of Birth
- Aboriginal and/or Torres Strait Islander (ATSI) status
- Language spoken at home
- How did you hear about 131120?
- Treatment center
- Topic discussed in the wig appointment (189 possible options)
- Referrals made
- Publications given
- Stage of cancer
- Cancer type
- Date of call
- Type of call (phone call / visit / e-mail)

Prior to January 2015, there were differences and discrepancies identified in the documentation of nurses working at Cancer Council Victoria, due to changes in practice and database functionality. For this reason, records made prior to this time were excluded from analysis.

Sub-analysis

A sub-analysis was conducted on the topics that nurses had recorded as having been discussed with wig service users in their wig appointments between January – August 2015.

Semi-structured interviews

Masters of Nursing Science students designed a custom questionnaire for use in a series of semi-structured interviews with people who had recently used the Cancer Council Victoria Wig Service (Appendix A). The questionnaire was workshopped with Cancer Council Victoria research staff with previous experience designing qualitative research questionnaires.

Commencing in February 2016, people who used the Wig Service and were scheduled for a six-week follow up call (as per usual protocol) were approached to see if they would like to take part in the interviews. During this phase, a total of 21 service users were contacted, and of these, 15 wig service users consented to participate in interviews. Reasons for not taking part included being unable to contact the service user, being unwell, or not having the time to participate due to treatment. The service users interviewed had their wig appointments between 22 December 2015 and 17 February 2016.

Interviews took place from 22 February – 4 March 2016, and were conducted by two Cancer Council Victoria nurses, one of whom had previous experience conducting qualitative semi-structured interviews with patients. This nurse trained the second nurse to conduct interviews. Neither of the nurses conducting the interviews had any prior contact with the wig service users they interviewed.

The interview recordings were transcribed and de-identified by the students at Cancer Council Victoria and analysed thematically for themes and subthemes.

RESULTS

Phase 1 Results

Retrospective audit demographics

Table 1a: Phase 1 Demographics (Gender) Wig Service Users from November 2012 – August 2015 (n = 654)		
Gender	Number	Percentage
Female	649	99.2
Male*	5	0.8

* CCV's Wig Service does not stock male wigs onsite, however the service does issue vouchers to any male cancer patients affected by hair loss to help offset the cost of purchasing a wig at a reputable retailer.

Table 1b: Phase 1 Demographics (Age) Wig Service Users from November 2012 – August 2015 (n = 654)		
Age	Number	Percentage
< 20	7	1.1
20-29	24	3.7
30-39	45	6.9
40-49	131	20.0
50-59	146	22.3
60-69	137	20.9
70-79	82	12.5
80-89	16	2.4
Age not recorded	66	10.1

Table 1c: Phase 1 Demographics (Country of Birth) Wig Service Users from November 2012 – August 2015 (n = 654)		
Country of Birth	Number	Percentage
Australia	270	41.3
England	24	3.7
Italy	11	1.7
India	10	1.5
Philippines	9	1.4
Greece	8	1.2
New Zealand	7	1.1
China	6	0.9
Vietnam	6	0.9
Other COB	68	10.4
COB not recorded	235	35.9

Table 1d: Phase 1 Demographics (Aboriginal and Torres Strait Islander Status) Wig Service Users from November 2012 – August 2015 (n = 654)		
ATSI	Number	Percentage
No	424	64.8
Yes	4	0.6
ATSI status not recorded	226	34.6

Table 1e: Phase 1 Demographics (Diagnosis) Wig Service Users from November 2012 – August 2015 (n = 654)		
Diagnosis	Number	Percentage
Breast	254	38.8
Ovary	46	7.0
NHL	45	6.9
Lung	44	6.7
Brain	17	2.6
Stomach	16	2.4
Other	128	19.6
Diagnosis not recorded	104	15.9

As discussed previously, to address differences and discrepancies in nurse documentation, new data entry standards were introduced from 1 January 2015.

Number of wig appointments by month

Table 2: Wig Appointments by Month Wig Service Users from November 2012 – August 2015 (n = 654)		
Year	Number of Appointments	Average Appointments per Month
2012	10*	5
2013	225	18.8
2014	241	20.1
2015	178**	22.3

* Service started in November 2012

**Data for 1 January 2015 – 31 August 2015

Wig service users by postcode

Wig service users are routinely asked for the postcode they live in (Table 3a).

Location	Number	Percentage
Melbourne*	563	86.1
Rural	62	9.5
Interstate	10	1.5**
Not recorded	19	2.9

*The Melbourne Statistical Division includes the Mornington Peninsula Shire and Yarra Ranges Shire ⁵.

**Nine service users gave an NSW post code as their home post code and 1 user gave a South Australian post code.

Location	Number	Percentage
Barwon	12	19.3
Goulburn	11	17.7
Central Highlands	8	12.9
Gippsland	8	12.9
East Gippsland	7	11.3
Loddon	7	11.3
Western Districts	3	4.8
Wimmera	3	4.8
Ovens – Murray	2	4.8
Mallee	1	1.6

Service users gave their home postcodes from as far away as: Hamilton, Port Campbell and Portland in the south west of Victoria; Minyip and Walpeup in the north west; Howqua and Yackandandah to the north east of Melbourne; and Bairnsdale, Lakes Entrance, and Paynesville to the east.

Sub-analysis: topics discussed at wig appointments

138 people had wig visits between January – August 2015 and of these 48 (34.8%) had no topics documented apart from “CCV Wig Service” and “Wigs / Headwear”. The remaining 90 (65.2%) people were documented as discussing one of more topic other than “CCV Wig Service” and “Wigs / Headwear” with their nurse at their wig visit.

Of the 90 people who discussed at least one non wig-related topic at their wig appointment:

5 or less topics discussed at wig visit	= 70 (78.65%)
6 or more topics discussed at wig visit	= 19 (21.35%)
Total	= 89*

*One person had two wig visits and discussed 6 topics at one visit and 3 topics at the other. Those visits are excluded from this breakdown.

The following tables (4a-4d) show the diversity of topics of discussion between wig service users and the nurse who conducted their wig appointment. Overall, 55 topics were documented as having been discussed in wig appointments between 2012 – 2015. These topics were analysed into four general categories: Treatment; Psychological / Emotional Support; Referrals and Patient Navigation; Other Miscellaneous Topics.

Table 4a: Phase 1 Topics Discussed at Wig Appointments	
Wig Service users January – August 2015 (n = 138)	
Topics: Treatment	
Chemotherapy	47
Side Effects	47
Treatment / Management	26
Radiotherapy	16
Surgery	13
Medicines / Drugs	11
Symptoms of Disease	5
Reconstructive / Cosmetic Surgery	3
Clinical Trials	2
Complementary and Alternative Medicine (CAMS)	2
Hormone Therapy	2
Targeted Therapies	1
Treatment other than cancer	1
At least one of the above topics	64

Table 4b: Phase 1 Topics Discussed at Wig Appointments	
Wig Service users January – August 2015 (n = 138)	
Topics: Psychological / Emotional Support	
Psychological / Emotional Support Information	22
Children	5
Sexuality	4
Self-image / Self-esteem	3
Partner / Family Issues	2
Recurrence	1
Prognosis / Survival Rates	1
Mediation / Relaxation	1
Death and Dying	1
At least one of the above topics	31

Table 4c: Phase 1 Topics Discussed at Wig Appointments	
Wig Service users January – August 2015 (n = 138)	
Topics: Referrals / Patient Navigation	
Look Good Feel Better	21
Cancer Connect Program	11
Cancer Support Group	10
Holiday Break Program	7
Cancer Council Financial Assistance Program (FAP)	4

Cancer Council Pro Bono Financial Planning Program	3
Social Work	3
Telephone and Internet Support Groups (TISG)	3
Cancer Council Psychosexual Counselling Service	2
Cancer Connections Website	2
Refer to Patient's Specialist	2
Refer to GP	1
Cancer Nurse Specialist	1
Professional Counselling	1
Dietitian	1
Living with Cancer Education Program (LWCEP)	1
At least one of the above topics	32

Table 4d: Phase 1 Topics Discussed at Wig Appointments	
Wig Service users January – August 2015 (n = 138)	
Topics: Other	
Financial Issues and Services	5
Pathology Results	2
Metastasis / Advanced Disease	2
Hair Donation	1
Survivorship	1
Rehabilitation	1
Palliative Care	1
Ostomy / Stomal Services	1
In-home Services	1
Pap Test Provider	1
Exercise	1
Rural	1
Early Detection	1

Phase 2 Results

Semi-structured Interviews Demographics

Table 5: Phase 2 Demographics				
Wig Service Users interviewed December 2015 – February 2016 (n = 15)				
Participant	Age	Cancer Type	Treatment Centre	Comment
1	68	Breast	Western (Sunshine)	Country of Birth (COB): Greece*
2	45	NHL	Western (Sunshine)	
3	41	Breast	Western (Sunshine)	
4	60	Breast	Dandenong	
5	57	Lung	La Trobe Regional	Husband also participated
6	48	Breast	Monash	
7	47	Breast	Peter Mac	COB: South Africa
8	50	Lung	John Fawkner	

9	49	Breast	Olivia Newton-John	
10	46	Breast	Austin	
11	71	Ovary	Royal Women's	
12	60	NHL	RMH	
13	16	Hodgkin's	Monash	Interview conducted w/ mother, family identifies as Sri Lankan
14	55	Breast	Ringwood Private	COB: China, language spoken at home: Cantonese
15	49	Breast	Mercy	
Average	50.8*			

NB: All participants were female

* COB where not otherwise identified was Australia

** Average age of all wig service users 2012 – 2015 was 55.2 years

Five main themes

Responses of the 15 wig service users were analysed into five overarching themes: (i) Booking, travel to and arrival at the wig appointment; (ii) Experience and satisfaction with the wig appointment; (iii) Treatment and support discussed in the wig appointment; (iv) Satisfaction with the wig; and experience of hair-loss and; (v) The value of the wig service.

Theme 1: Booking, Travel to and Arrival at the Wig Appointment

Wig service users who were interviewed spoke of their experiences making a booking for the Wig Service, how they travelled to their wig appointment; their feeling on arriving at the Cancer Council Victoria building; and the time they spent waiting for their appointment to begin.

1.1. Making the booking

Fourteen of the 15 interview participants reported that they had no problems with booking their wig appointment. Reflections on this component of the service included:

- “easy”
- “I found the lady very friendly and helpful”
- “no problems”
- “quite straightforward”
- “She was really nice. I had a chat to her and she asked me questions about my cancer. I think she was just checking on my wellbeing. No drama at all.”

The one participant who was not completely satisfied with the booking process said she found the booking process involved some “counseling” which is not what she needed at the time:

“I wanted to make a booking and I’m quite busy. I’ve got a business, got lots of things going on so for me I just wanted to make the booking whereas the

conversation was perhaps more than I wanted. It didn't make me upset or anything it was, you know, I just wanted to get on with it". (Participant 2)

1.2. Travel to the wig appointment

All of the participants traveled to their wig appointments by car. Not all of the people interviewed mentioned their travel time or whether they came with someone else to the appointment.

Table 6: Travel to the Wig Appointment			
Wig Service Users interviewed December 2015 – February 2016 (n = 15)			
Participant	Travel Time (mins)*	Who With	Comment / Issues
1	-	Cousin	Parking easy, found it easily
2	15	-	No trouble
3	-	-	Not difficult
4	50-60	-	-
5	45	Husband	-
6	20	By herself	A bit late because she had to get coins for the parking meter
7	-	Friend	-
8	25	Son	Parking was fine, no problems, doesn't like driving in the city herself
9	-	Sister	No big deal
10	30	Partner	Parking was fine, participant doesn't drive herself anymore
11	45	Husband	No problem but I wouldn't have wanted to drive myself
12	20	Sister	Participant had a fall getting out of the car
13	-	Parents	-
14	45	Daughter	Participant can't drive herself after her operation
15	-	-	Parking was crazy

**Travel time represents one way only*

Four of the 15 participants reported that they would not have felt confident, or could not have driven themselves to the appointment so relied on someone else to drive them.

Three participants reported that they had no problem with parking and only one participant reported difficulty finding a car park. One other participant reported that she was slightly late for her wig appointment because she had to go and find change for a parking meter

1.3. Arriving at Cancer Council Victoria

Most of the participants did not express any particular reactions to coming to the Cancer Council Victoria however three participants overall made mention of their thoughts on entering the building.

Participant 6 said:

“It’s a beautiful building to walk into. You instantly feel calm and relaxed. It’s a gorgeous building to enter and the staff are smiley, and very kind, and welcoming.”

Participant 13 was a mother responding on behalf of her 16 year old daughter who had just started treatment for Hodgkin’s Lymphoma. She said coming to Cancer Council Victoria brought home the reality of their daughter’s situation:

“We came to the city and saw the building and all that. Me and my husband looked at each other and like: ‘this is a real thing?’ We had gone through the first set of chemo but even then it was like it was we were in a dream world at that time My husband is going through a bit of a hard time with all this, so we just wanted to get the wig and get out of there, just walk out, and even my daughter didn’t want to stay there for long.”

Participant 5’s husband said that he and this wife found it “very hard to walk in” to the Cancer Council Victoria building in St Kilda Road but went on to say that “by the time we walked out the anxiety, it lessened”.

1.4. Waiting time

No participant reported waiting more than 10 minutes between arriving at Cancer Council Victoria and the start of their wig appointment.

Theme 2: Experience and Satisfaction with the Wig Service

Some of the wig service users who were interviewed did not know the staff member was conducting the wig appointment was a nurse. Interviewees were asked about their perceptions of the nurse that conducted their appointment and about their satisfaction with the Wig Service as a whole.

2.1. Did the participants know the Cancer Council Victoria staff member was a nurse?

Ten of the 15 participants knew that the staff member conducting the wig appointment was a nurse.

Two participants did not know that the staff member was a nurse.

Two participants were unclear of whether the staff member was a nurse but thought they were when prompted.

One participant had no recollection of whether the staff member was a nurse or not.

2.2. Participants' perception of the nurses

All of the participants gave positive feedback about the manner and the knowledge of the nurses conducting the wig appointments. Comments included:

- *“Very pleasant ... very approachable”*
- *“Absolutely lovely”*
- *“Excellent, everything I asked she helped me with”*
- *“The nurse that done the wig was very good. She was lovely. She sort of put me at ease. Very caring”*
- *“Very nice, very informative, very understanding”*
- *“Really good, really helpful, really knowledgeable”*
- *“Thorough, patient, I didn't feel rushed at all. Very polite, I felt very comfortable”*

None of the participants had any negative comments about the nurses' manner or their knowledge of cancer and cancer treatment.

One of the 15 participants reflected on her nurse's knowledge of wigs and wig fitting. Participant 7 mentioned that the nurse was unable to fit her wig properly, and decided to come in for a second visit to get a different wig that fitted her better. She said of her nurse:

“She was lovely. She was very helpful; however she did not really pay attention to whether the wig fitted. I could tell it was a bit big on my head and she showed me how the wig could be adjusted around the perimeter of the wig, however when I got home and put the wig on for the first time I realised that the actual wig itself, the whole internal part was too big for my head”.

2.3. Satisfaction with the Wig Service

Apart from the one participant who had received a wig which didn't fit properly all of the other participants (14/15) expressed satisfaction with their experience of the wig service, and most expressed a very high level of satisfaction. Comments included:

- *“100% satisfied, it's a lovely service, I was pleased to find something that really suited”*
- *“More than satisfied, it's awesome, I couldn't fault it”*
- *“It couldn't have been better”*
- *“Well and truly above what I expected, I thought it would be here are a couple of wigs here, pick one you like, and off we go to the next one”*
- *“Fantastic, absolutely fantastic, I just couldn't believe it”*

Participant 5 contrasted the privacy of the experience with the Cancer Council Victoria Wig Service with a wig service she had seen in operation at a hospital:

“I've had another experience with the hospital and that was (pause) if I hadn't been and done what I'd done with St Kilda [Cancer Council Victoria] I would have been, I think I would have been devastated. [At the hospital] they had all the wigs in a cupboard and they had to walk past everybody and take the wigs into another room and I felt that was very embarrassing to walk past men, and women who were having chemo. I just felt lucky for me I'd already got [a wig]”.

Theme 3: Treatment and Support Discussed in the Wig Appointment

All of the wig service users were asked about topics they discussed in their wig appointments that did not relate directly to the wig.

3.1. Topics discussed

As the interviews were conducted several weeks after the wig appointments, a couple of participants found it difficult to remember all the details of the discussion they had had with their nurse.

Five of the 15 participants reported having discussions with the nurse taking the wig appointment about treatment and support related issues. Issues discussed included:

- Side effects of treatment
- Anxiety about upcoming surgery
- Anxiety about the uncertain outcome of treatment
- Discussion of specific medications
- Central line management
- Information about other support services that are available

Discussing the support she had received from the nurse in her wig fitting, Participant 6 stated:

“I was so overwhelmed by how kind everybody was. The nurse was superb. I got more information from her about the whole process than just about anyone else I’ve spoken to. She really took a lot of time to guide me through my side effects, lots more than just the wig, lots of information and ideas about what to do on this journey. I’d had an appointment the day before with the radiation oncologist who had been pretty brutal and had left me reeling a little bit from that appointment. I was able to discuss that with her and she really put me at ease and put me back on track”.

Only one participant said there was a topic she would have liked to discuss (complementary and alternate therapies), but did not have the chance.

Five participants reported that, while they did not have any specific issues they wanted to discuss, they felt there were barriers to discussing non-wig related issues. Reasons included:

- The perception that there was time pressure: *“we only had a short half an hour.”* (Participant 14)
- The perception that the focus of the wig fitting was only about wig: *“the focus of the session is clearly on wigs. I thought: ‘was it appropriate?’ You’re in a wig room. It [treatment and support] basically doesn’t seem to be what the appointment is about”.* (Participant 15)
- Not wanting to upset a family member who was with them at the appointment: *“I didn’t go that deep into it all because my husband is having a hard time of it all.”* (Participant 13)

At least one of these participants could remember being offered the option of calling Cancer Council's 13 11 20 Information and Support line later if she had other things she would like to discuss.

There was also one participant who found her wig appointment involved too much discussion of treatment and support services. This was the same participant who expressed similar feelings about the booking phone call.

The remainder of the participants interviewed either had no treatment and support topics they wished to discuss, or could not recall exactly what they had discussed with their nurse at the time of their appointment.

Theme 4: Satisfaction with the Wig

Interviewees were asked whether they were satisfied with the wigs they had received and how often they wore them.

4.1. Wig Usage

Table 7: Wig Usage		
Wig Service Users interviewed December 2015 – February 2016 (n = 15)		
Frequency	Number of participants	Heat mentioned as a barrier
Daily	6	2
3-4 times per week	2	1
On special occasions only	3	2
Never	1	-
Unsure, too early to tell	3	1

The six participants who wore the wig daily reported wearing the wig “all day”, “about six hours per day” and “every time I leave the house and whenever I receive visitors”. The two participants who wore the wig every second day wore it for about two hours per day, although one reported wearing it for longer periods when she went out on Saturday nights.

Of the three participants who reported wearing it on particular occasions:

- One participant reported wearing the wig for approximate half a day per week and only wearing it for work meetings
- One reported wearing it for special occasions, wedding, christenings etc.
- One had only worn the wig once to have a family portrait taken

As mentioned, the wig visits discussed in these interviews were conducted between late December 2015 and mid-February 2016. As this is the hottest time of year in Melbourne, six participants mentioned heat as a barrier to using the wig or a reason they may not use the wig for long periods. Despite this, some of those that mentioned heat as a factor still reported using the wig for six or more hours per day.

4.2. Culturally and linguistically diverse participants

Two participants were of non-European decent were the only participants who had not worn the wig they received from the Wig Service. The mother of the 16 year old girl who was

being treated for lymphoma were from a Sri Lanka and said this about finding a wig that suited her daughter:

“Because we are Sri Lankan there weren’t many suitable wig styles that were like what her hair looked like. There were a lot of blonde wigs”. (Participant 13)

She went on to say that her daughter had chosen a wig with a short fringe even though she usually wore her fringe long and although the daughter had said she was pleased with the wig at the time of the appointment, when she got home she has not worn the wig and only every wore a hat when going out.

Participant 14 was born in China and speaks Cantonese at home. On finding a wig that suited her she said:

“When I got there, [there were] not many you can choose, you know? Not many, only a few, because when compared to the others they are all not suitable for me, because we’re Asian and got the black colour hair.”

She went on to say the wig she had received was acceptable but not perfect. She had not worn it yet as her hair had only just started to fall out at the time of the interview.

4.3. Wig satisfaction

Apart from the mother of the 16 year old girl from the Sri Lankan family, and the Chinese born participant, 12 of the other 13 participants expressed satisfaction with the wig they received. The remaining participant said she was unsure of her level of satisfaction as it was too early to tell. Comments from the satisfied users included:

- *“They’re really good, they look so real” (Participant 3)*
- *“I don’t know where I would be if I didn’t have it” (Participant 5)*
- *“Yeah, I love it, everybody that sees it just loves it so yeah, that in itself gives you so much more confidence for you to go ‘wow that looks amazing” (Participant 10)*

Participant 10 said this of one of her friends seeing her wig for the first time:

*“One of my friends when I turned up last week on our holiday he just thought I had dyed my hair red and I was in the caravan and I took my wig off and he went: ‘oh my god you’re f***ing bald! I thought you dyed your hair”.*

Only one participant reported that the wig she had chosen looked like her original hair. Six participants noted that the wig did not look like their original hair but all still said they liked their wigs:

- *“My daughter actually spotted this one which was different in style to what I expected to have. So I tried that one on and as soon as I put it on I thought well that is obviously the best one for me and I quite like it. It’s been very good. A lot of people have told me how natural it looks”. (Participant 11)*

- *“It’s quite different [from her normal hair]. It’s not a problem; [people] look at it and think: ‘oh geez, that really suits you’.”* (Participant 12)

Theme 5: Experience of Hair-loss and the Value of the Wig Service

Wig service users who were interviewed were asked about why they wanted to obtain a wig from the Cancer Council Victoria Wig Service. There was a diversity of responses; however some key subthemes emerged quite strongly.

Several people described the distress that losing their hair had caused them and found it challenging to their self-identity and many of the interviewees described not wanting to be the center of attention or wanting to maintain a sense of normalcy.

Others interviewees were worried about the effect their hair-loss and baldness may have on their children, their parents or their partners.

There were a couple of people who described finding unexpected positives in their experience of cancer related hair-loss and obtaining a wig from the Wig Service.

Finally, financial and work related imperatives emerged as a theme with a majority of those interviewed.

Table 8: Experience of Hair-loss & the value of the Wig Service	
Wig Service Users interviewed December 2015 – February 2016 (n = 15)	
General distress (unable to articulate further)	3
Dressing up, having fun with it, positives about the feeling of baldness	2
Not wanting people know you are sick, not wanting to be the center of attention, wanting things to be normal	9
Not caring what the people think	1
Not wanting to confront or distress:	
People in public	1
Children or grandchildren	3
Elderly parents	2
Husband	1
Loss of identity, not feeling like “me”	3
Loss of femininity	5
Embarrassment, social anxiety	1
Not wanting to be reminded of my illness	2
Financial hardship, the expense of buying a wig	8
Needing the wig for work	2
Timeliness of obtaining a wig from CCV	2
Wearing the wig for specific social occasions	2

5.1. General distress

Several participants described being distressed by the experience of losing their hair. Some found it very difficult to articulate the experience. Participant 5 broke down in tears when trying to explain how she had felt. Her husband took the phone for a brief period of time and said:

“It was so much anxiety that when she was having a shower she stopped washing her hair because every time she washed it, it would start coming out. She’s getting upset that’s why I’m stepping in”.

Participant 1 said of losing her hair:

“The chemo was not stressing me as much as the fact that I was going to lose my hair”.

5.2. Positive reactions

There were exceptions to these negative feelings and experiences and a couple of participants had found some positives in their experience. Participant 2 said of losing her hair:

“Going bald hasn’t been an emotional experience for me. I actually found it quite liberating”.

Both Participant 2 and Participant 6 described unexpected pleasures of losing their hair. Participant 6 said:

“The incredible feeling of a breeze on your scalp for the first time since you were a baby, it’s kind of amazing. Stepping into a shower with water running onto your naked scalp is another blissful experience ... you can focus on the negatives or you can focus on the positives.”

5.3. Unwanted attention

The most common view expressed among the 15 participants was the feeling of not wanting their baldness to be the center of attention in public. Participant 10 said:

“Going out for tea people just take a couple of steps from you when they see you, like: “oh there is something wrong with her.”

Participant 9 spoke of not wanting to go into the shops she normally shopped at without hair:

“The first time I did shave my head with the first treatment. The next day, I went for a powerwalk ... and I used to always go to the milk bar to get the newspaper. I didn’t go to the milk bar with the man that knows me; I went to another strange milk bar, because I didn’t feel comfortable”.

While nine of the 15 participants did express some variation of not wanting to be the center of attention in public, there were exceptions. Participant 4 had only wanted the wig because

her daughter wanted family portraits taken. About going out in public without the wig Participant 4 said:

“It doesn’t bother me. It’s not affecting me. I’m still me underneath even if I’ve got no hair”.

Participant 6, one of the participants who had described some quite positive attitudes towards losing her hairs, still had this to say:

“At the moment I’m going through a phase of embracing the baldness and being bald. Sometimes you’re quite happy to embrace that and stand tall and be that person. Then there are other days when you’re not. That’s when the wig is there for me. Some days I’ll want to blend in with the rest of the world and not see those sideways glances and recognition. I just want to be normal. The wig is that. It’s absolutely that. You walk past me with that wig, you and I have never seen each other before, you would not know I was wearing a wig”.

5.4. Confronting or distressing other people

The effect of their baldness on other people was prominent in the minds of a number of the participants. Three of the participants were worried about children or grandchildren in their families. Participant 5 had been using her wig to protect her grandchildren from knowing that she was sick and worrying about her:

“My granddaughter is only six and we haven’t said anything to her. We used to always do each other’s hair because I had long hair and the other day she said ‘Oh Nan, can I comb your hair please?’, and so I had to quickly say ‘it’s so hot today, how about we do it another day?’. If she saw me without hair she’d want to know. I just think that’s a little bit too much for a six year old”.

Participant 6 spoke of her eight year old son and ten year old daughter’s reaction to her baldness:

“I did actually have a pretty full on reaction from my daughter. It was her birthday on Monday and what we were going to take her to a shopping center for dinner and a movie with two friends, they’re small birthdays for both kids this year. She was furious and she said I don’t want a birthday. I don’t want to go out in public with you with no hair. It’s going to look really disgusting and it’s going to be really embarrassing. It was just so hurtful. It was hurtful for me but of course she was seriously hurting”.

Later in the interview Participant 6 said:

“It’s just so wonderful to have this option to have a wig because I think that they [her children] will really embrace it”.

Two participants spoke of using the wig to protect their elderly parents from worrying about their illness.

None of the people interviewed said that they wore their wigs when they were just with their husbands or partners and most did not think the wig had any real impact on their

relationships. Participant 9 said that she was not in a relationship and told of her experience of cancer related hair-loss as a single woman:

"I don't have a partner at the moment but I've got a friend ... who hasn't seen me for a while. He'd gone away and when he came back I was a bit sensitive and hesitant, because of how it was going to go with the scarf, because I had the scarf on. Once I got the good feedback, when he saw me with the wig, he goes 'Oh my God, you look like ... it looks like it's your hair but it's shorter'. I felt comfortable after that".

5.5. Changing the way people feel about themselves

Some participants focused on how losing their hair made them feel in themselves as opposed to the effect their baldness had on other people. Participant 9 summed up the feelings that a number of different participants expressed when she said:

"I remember two years ago a friend of mine was really sad and upset about losing her hair. I didn't say a lot. I kept on thinking: 'well your life is more important, don't worry about it.' I thought of it like 'how can she even think about it? About her hair?'. But once you go through it you realise what an idiot I was. When you go through it you sort of feel it can't happen, like something is stripped from you. Your identity. You don't feel like a woman. You feel like a patient or a sick person".

5.6. Financial situations and work

From a more practical point of view, a theme that came through strongly in a large number of interviewees was the idea of struggling financially during cancer treatment and the difficulty of affording a wig. Participant 8 said:

"I did go through a program at the hospital, the Look Good Feel Better session. The wigs were around \$300 and it was around November and I thought I'll just wait until after Christmas and when I did speak to the Cancer Council and they told me it was free. I was surprised. I didn't expect that at all and I thought well that's great and I've only been on one wage. My husband's the only one working and I just need all the financial help I can get".

In all, eight of the 15 people interviewed raised their financial situation as a factor in them deciding to use the Cancer Council Victoria Wig Service.

This financial imperative was also present with two of the participants who described needing the wig to go back to work. Participant 2 said that she found losing her hair a liberating experience but she found having the wig important from a work point of view:

"I don't want to be confronting people, and it's usually in a work sense that I don't want to draw attention that I've got cancer or anything but you know, I mean, I have a business locally so I have a profile within the community".

Speaking of her work situation Participant 6 said:

“I’d just recently qualified as a teacher. A school that I’d like to be employed in offered me a full time contract for term one. I was pretty overwhelmed that they’d offered me that. Having to knock it back was very difficult to do but I knew I couldn’t possibly do that sort of newish job ... I’d want to do it 100%. That’s exactly what I want this [wig] for. As soon as I get through this chemo treatment and I start my radiotherapy I can work full time back in the school and to be able to go back with hair will be superb. That’s really what I want. That will be what I do every single day. I will wear the wig”.

5.7. Specific social situations

Two people spoke of wanting the wig or using the wig for significant social occasions. Participant 9 recounted the following:

“It was my nephew’s wedding and I would have been in all the photos. I didn’t want to go. The wig saved me when I wouldn’t have been able to go. I would not feel comfortable to have a scarf and for people to feel uncomfortable... that’s what I felt. I didn’t want anyone to know”.

DISCUSSION

This is the first formal evaluation of a Wig Service for patients experiencing cancer related hair-loss in Australia. The results give significant insights into not only the operation of the Cancer Council Victoria Wig Service but also the experience of people affected by cancer-related hair-loss.

Demographics of the Wig Service users

Prior to January 2015, there was a lack of consistency in the way calls and visits to Cancer Council Victoria were documented by nurses and as such, Phase 1 had a significant amount of data missing from some data fields. This means that the study was unable to report on several topics including: where wig service users first heard about the wig service; which treatment center the wig service users were being treated at; and what language the wig service users spoke at home. Changes in documentation practice from 2015 onward mean these topics will be able to be reported on in the future.

In the Phase 1 data, only 419 of the wig service users had a Country of Birth (COB) recorded. Of these, 270 (64.4%) were born in Australia and 149 (35.6%) were born overseas. At the time of the 2011 census 68.6% of all Victorians were born in Australia and 31.4% of Victorians were born overseas⁶. Apart from Australia, the most common COB for wig service users were: the United Kingdom, Italy, India, the Philippines, and Greece. The most common COB for Victorian women as of 2011 were: the United Kingdom, India, China, New Zealand, and Italy⁷.

People who identified as Aboriginal and Torres Strait Islanders made up 0.6% of wig service users. This compares to 0.7% of the Victorian population who identified as Aboriginal and Torres Strait Islander in 2011⁸.

Breast Cancer was the most common diagnosis among wig service users at 38.8% followed by Ovarian (7.0%), NHL (6.9%), Lung (6.7%) and Brain (2.6%). According to the Victorian Cancer Registry the most common cancer diagnosis for Victorian women in the past five years were: Breast (37.1%); Bowel (16.5%); Lung (10.5%), Melanoma (9.5%); and Uterus (6.4%). Lymphoma was sixth at (5.9%), Ovary was ninth at (3.4%) and Brain cancer was not rated within the ten most common cancers to affect Victorian women⁹. It is likely the differences seen here are a result of the differences in treatment modalities between the types of cancer.

The mean age of wig service users was 55.2 years. The youngest person to use the wig service was seven years old and the oldest, 85.

Taken as a whole, the Phase 1 data shows that the Wig Service has reached a wide and broadly representative range of Victorian women affected by cancer-related hair-loss.

Demand for the Service

In January 2013, the third month that the Cancer Council Victoria Wig Service had been operating, there were 21 wig appointments. This is higher than the average monthly number of wig appointments (19.2 per month) across the program as a whole and speaks to the substantial unmet need that existed before the Wig Service began operation. Each year of the Wig Service's operation has seen an increase in the average number of appointments per month, which demonstrates a level of acceptability to the target population.

Accessibility

As would be expected with a program that operates from a single centre, the results show some problems with accessibility. Rural Victorians made up 9.5% of Wig Service users. Many of these people would have needed to travel several hours by car to access Cancer Council Victoria's Wig Service or be staying in Melbourne. This suggests there is a lack of options for accessing affordable wigs in rural Victoria and that the need is great enough that people will go to a significant amount of trouble to access a wig.

Despite the fact that the Cancer Council Victoria building is conveniently accessible by public transport from Melbourne's CBD, the interviews conducted in Phase 2 of the study suggest that lack of access to a car or someone to drive wig service users to their appointment may also be a barrier for potential wig service users who live within the Melbourne statistical division.

The Role of the Nurses

The benefits of having wig appointments conducted by experience cancer nurses becomes obvious both from the Phase 1 sub-analysis of topics that were discussed by wig service users and the accounts given by the interviewees in Phase 2. The benefits for many of the wig service users go well beyond simply obtaining a wig. The wig appointments at the Cancer Council Victoria Wig Service are frequently complex and meaningful therapeutic

interactions. Topics relating to treatment, emotional support and many other aspects of cancer treatment are discussed in the majority of wig appointments and wig service users are often referred on to other services and avenues of support as needed.

Lack of Induction for Service Users

It is clear from the interviews that there is a lack of consistency in the way wig service users are introduced to their wig appointments. Some wig service users thought they weren't supposed to talk about non-wig-related issues in their appointment. Others were not sure the staff member taking the appointment was a nurse. These issues may be easily solved by using a standardised induction procedure for wig service users.

The Individuality of the Service Users

There was significant diversity of experiences of cancer related hair-loss among users of the Wig Service. Some reacted positively when arriving at the Cancer Council Victoria building while others found it an anxious and confronting experience. Some were appreciative of the various elements of support they received while others just wanted to obtain a wig and did not feel the need for any other support. The overwhelmingly positive feedback from service users about the nurses conducting the wig appointments suggests that in the majority of cases, nurses are assessing the needs of the service users accurately and meeting their individual needs effectively.

Wig Use

The high levels of wig use reported by most of the service users in Phase 2 of the study confirm that the wigs supplied by Cancer Council Victoria's Wig Service are meeting the needs of service users. Although most interviewees reflected that the wigs they chose did not closely resemble their original hair, most reported being very satisfied with the wigs that they had received. The only group that were not satisfied were the two service users from culturally and linguistically diverse backgrounds.

The Value of the Wig Service

The accounts that interviewees gave of their cancer-related hair-loss and its impact on their lives reinforces the need for Cancer Council Victoria's Wig Service. While some participants spoke about enjoyable aspects of losing their hair or trying on their new wig, the majority of service users described their hair-loss in negative terms and for some, this was overwhelmingly negative. The negative psychological impact, when combined the financial impact of ongoing cancer treatment, underpins the value of being able to provide these wigs at no cost to service users. Given the positive impact described by the 15 wig services users interviewed for this study, it is hoped that these results would be able to be generalised across the more than six hundred Victorians who have used the service since November 2012. These figures and reflections demonstrate a significant impact over time, using a model that is feasible, sustainable and able to meet the needs of Victorians affected by cancer.

CONCLUSION

This study demonstrates the value of Cancer Council Victoria's free nurse-led Wig Service to Victorians experiencing cancer-related hair-loss. The service helps to reduce the psychological impact of cancer-related hair-loss and it is particularly important for those experiencing financial disadvantaged or changes in their ability to work as a result of their cancer treatment.

Although these results provide a strong endorsement of the Cancer Council Victoria Wig Service, there are areas that can be improved. For example, a better range of wig for users from culturally and linguistically diverse backgrounds would allow the service to better meet the needs of this population. In addition, consideration should be given to strategies that can make the service more accessible to rural Victorians and those with limited transport options.

In spite of these limitations, the Cancer Council Victoria Wig Service is an important service for many Victorians suffering from cancer-related hair-loss. The wigs that participants had received helped them in many different aspects of their lives and overall, the impacts were positive and significant. When asked if she would like to add anything that had not been covered in the interview, Participant 3 said:

"Thank God. Thank God I got my wig from you because I feel like a different person. No, more like a normal person."

RECOMMENDATIONS

1. That Cancer Council Victoria continues to offer the Wig Service in its current free nurse-led form and take steps to promote the positive impact of the service to donors to ensure the ongoing viability of the service.
2. To examine options to expand the Wig Service or increase the accessibility of the service for people experiencing cancer related hair-loss in rural areas and people who live in Melbourne but have limited access to transport.
3. Introduce a standardised introduction for service users for when they first arrive at the appointment so they are:
 - aware that it is an experienced cancer nurse who will conduct their appointment
 - aware of the length of the appointment so they do not feel a perceived time pressure when choosing their wig or discussing issues with the nurse
 - Informed of the range of services that they can access and ensure service users get the full benefit of their interaction with the service.
4. Look into offering a wider range of colors and styles of wigs to better cater for the users from culturally and linguistically diverse backgrounds.
5. As this is the first formal evaluation of a wig service of this kind in Australia, it is recommended that the results be disseminated to Cancer Councils in other states and other organisations with an interest in the psychosocial care of cancer patients who may be interesting in establishing a wig service in the future.

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APPENDIX

Wig Audit – Phase II

Semi-structured Interview Questions

Preamble: Thank you for agreeing to take part in this interview. Please answer the following questions as honestly as possible. Information you give will be de-identified and will in no way alter any treatment you may receive in the future. You have to answer any of the questions and you do not want to continue with the interview you may stop at any time.

Q1: Where did you first hear about the Cancer Council Victoria wig service?

Q2: Why did you decide to make a booking with the CCV wig service?

PROMPT: What was it about losing your hair that concerned you?

Q3: Thinking back to the time of your appointment did you have any other concerns relating to your cancer and treatment?

PROMPT: Could you tell me more about that?

Q4: Could you describe your experience of making the booking for the wig appointment?

PROMPT: Did you have any difficulties making the booking?

Q5: How did you travel to your wig appointment?

PROMPT: Was it easy / difficult for you to get to the appointment?

Q6: Could you please tell us about your experience at CCV on the day of your appointment?

PROMPTS: Did you have to wait long for your appointment after arriving at CCV?

How were you treated by the CCV staff?

Were you satisfied with your wig appointment? In what way?

Q7: How would you describe the CCV staff member who conducted your wig appointment?

PROMPTS: Did you find them friendly and approachable?

Did they know enough about cancer treatment, hair loss and wigs to answer your questions?

Q8: How often have you worn your wig over the past six weeks?

PROMPTS: Why have you (or why have you not) been wearing it?

Have you been satisfied with the wig you received?

Q9: Thinking back to the reasons you made the wig service booking (QUOTE the participant's answers to Q2.) would you say those issues were effectively addressed by the wig you received?

Q10: Thinking back to the other issues you mentioned being concerned about at the time (QUOTE the participant's answer to Q3.) was the CCV staff member able to address those issues with you?

PROMPT: In what way?

Q11: Do you feel like the having the wig changed the way you felt?

PROMPT: Can you tell me more about that?

Q12: Do you feel like the wig changed the way you interacted with:

- Your partner (if you have one)?
- Your friends?
- Your family?
- The general public?

Q13: Is there anything else you would like to tell us about your experience of cancer related hair-loss and using the CCV wig service?