

Chemotherapy information in paediatric oncology: What do families want?

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Introduction

- There are currently limited resources available to paediatric cancer centres for patient and carer chemotherapy education.
- Consumer medicines information (CMI) is often inappropriate as paediatric chemotherapy protocols are complex and many chemotherapy medications in paediatric oncology are used outside of their approved indications.

Method

- Families at the WCHN Michael Rice Centre for Haematology and Oncology completed a questionnaire regarding their preference for written information about chemotherapy from January to March 2016.
- They were asked to comment on examples of publicly available paediatric chemotherapy information leaflets for Vincristine produced by the Royal Children's Hospital Melbourne (Figure 1), Starship Blood and Cancer Centre (Figure 2), and the CMI leaflet by MIMS Australia (Figure 3).

Results

Information delivery

- Twenty two (n = 22) completed questionnaires were returned.
- 50% preferred printed information
- 45% preferred both printed and electronic information
- 5% preferred electronic information

Verbal counselling by a pharmacist in addition to written information was considered important by 91% of families.

Views on information

Families considered the following information as extremely important – the type (95%), time of onset (77%) and likelihood (73%) of side effects, as well as what to do when they occur (82%) (Table 1).

Table 1: Degree of importance of specific types of information

	Extremely important n (%)	Important n (%)	Moderately important n (%)	Somewhat important n (%)	Not very important n (%)
How medication works	13 (59)	4 (18)	4 (18)	1 (5)	0
Types of cancer treated	3 (14)	6 (27)	11 (50)	2 (9)	0
Frequency of administration	9 (41)	7 (32)	4 (18)	2 (9)	0
Types of side effects	21 (95)	1 (5)	0	0	0
Likelihood of side effects	16 (73)	6 (27)	0	0	0
Time of onset of side effects	17 (77)	4 (18)	1 (5)	0	0
Response to side effects	18 (82)	4 (18)	0	0	0
Tests to monitor side effects	7 (32)	11 (50)	4 (18)	0	0
Cytotoxic safe handling information	14 (64)	5 (23)	1 (5)	2 (9)	0
Haem Onc Pharmacy contact details	9 (41)	8 (36)	2 (9)	2 (9)	1 (5)

Views on layout

Comments that best represent the feedback received by families are presented below.

Side effects (continued)

- Low energy
- Muscle weakness

Are

- Fever
- Hoarse voice
- Choking/swallowing
- Difficulty walking
- Delirium

Additional information

- Vincristine can cause damage to nearby tissue if the medication leaks out of the vein. If this occurs, pain and swelling are usually immediate but may occur later. Notify the ward or clinic staff if your child complains of pain at the injection site.
- Avoid excessive exposure to sunlight and use a high SPF sunscreen.
- Keep ALL medications out of the reach of children.

For further information, or to discuss any concerns you may have about your child's medication, please feel free to contact the Children's Cancer Centre of your child's treating hospital.

RDH Oncology Pharmacy (08) 9545 6200 or Menzies Children's (08) 9544 7880

Figure 1: Vincristine, Royal Children's Hospital Melbourne

"Side effects are listed in order of likelihood of occurrence"

"Don't like it. No explanation about what vincristine is and how it works. Very limited information about the drug, what it's used for and when to be concerned about side effects"

"Information is bullet point under clear headings that can easily be located. Enough information included to be aware and not overwhelmed"

What is Vincristine?

Vincristine is an anticancer agent used to treat different types of leukaemia and child cancers. It can also be used for some cancer conditions.

How does it work?

Vincristine works on cells to prevent DNA synthesis. Vincristine disrupts the formation of spindle apparatus, which stops the cell multiplying during mitosis. A specific place in the cells of red cells. Vincristine also interferes with axons and can prevent conduction by paralyzing the use of motor acid related proteins and.

How is it given?

Vincristine is administered as an intravenous (IV) push or as a short infusion over 15 minutes.

Special instructions:

- Vincristine can cause or worsen constipation. Your doctor may prescribe a stool softener or laxative if you have constipation.
- You may be prescribed a medicine to help with vomiting, hugging or pain that you may have with vincristine treatment.
- Tell the nurse right away if you have pain or redness at the site where the injection is given.

Possible Side Effects:

- Vincristine can cause or worsen constipation. Your doctor may prescribe a stool softener or laxative if you have constipation.
- You may be prescribed a medicine to help with vomiting, hugging or pain that you may have with vincristine treatment.
- Tell the nurse right away if you have pain or redness at the site where the injection is given.

Figure 2: Vincristine, Starship Blood and Cancer Centre

"What is vincristine? How does it work? What is it used for? Particularly liked the special instructions. When side effects are likely to be experienced"

"Congested and crowded. Not as easy to read. Don't like layout"

"Love this one! Like the way it is broken down and the information it includes. I especially love the side effects section and how it is broken into likely, less likely, rare"

"Doesn't explain when to be concerned about side effects and see the doctor before planned appointment if needed i.e. Contact hospital"

What is in this leaflet?

This leaflet contains important information about Vincristine Sulfate Injection. It does not contain all the information you need to know about this medicine. It does not contain all the information you need to know about this medicine.

Before you are given Vincristine Sulfate Injection

When your doctor tells you to take this medicine, you should read this leaflet carefully. It contains important information about this medicine. It contains important information about this medicine.

What Vincristine Sulfate Injection is used for

Vincristine Sulfate Injection is used to treat different types of leukaemia and child cancers. It can also be used for some cancer conditions. It can also be used for some cancer conditions.

How Vincristine Sulfate Injection is given

Vincristine Sulfate Injection is given as an intravenous (IV) push or as a short infusion over 15 minutes. It can also be used for some cancer conditions. It can also be used for some cancer conditions.

Side effects

Vincristine Sulfate Injection can cause or worsen constipation. Your doctor may prescribe a stool softener or laxative if you have constipation. It can also be used for some cancer conditions. It can also be used for some cancer conditions.

Figure 3: Vincristine, CMI by MIMS Australia

"Even more informative with information on taking other meds and more in depth about side effects"

"Too much information about overdoses, when not to take it, .."

"Headings allow you to find information without reading all of it"

"Seems a bit broad / vague. Not as useful as the more detailed explanation of side effects given in the others. I don't think it would help if I was at home wondering if I should call the hospital?"

Discussion and Conclusion

Parents preferred a simple layout of information with bullet points, tables and clear headings.

They valued specific and practical information on:

- How each medication works
- Explanation of symptoms
- The reversibility of side effects
- The role of supportive care medicines.

The publicly available paediatric chemotherapy leaflets and CMI do not adequately address the information needs of paediatric oncology families.

This information can be used to develop written information which meets paediatric oncology families' preferences to improve the relevance and quality of patient chemotherapy education.