

A summary of the findings from the LOROS research project which explored the experiences and views of family in relation to injectable 'just in case' medications at home

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BACKGROUND & AIMS

It is generally seen as important to place injectable 'just in case' medications in the home as a way of managing symptoms and helping people stay at home. However, there had been no research about what family experiences and views on this were.

The primary aims of this study were to explore these experiences and identify ways to improve practice.

FINDINGS

- The vast majority (87%) of people indicated there were benefits to having 'just in case medications' available (chart 1).
- The majority expressed feeling "reassured" or "relieved" that medicine would be readily available when needed to provide symptom relief.
- However, some people found having the medicines "upsetting" or difficult for other reasons. For some, this was because they highlighted that death was imminent, others worried about storage, having responsibility for and potential waste of medication.
- Communication about the rationale for medications was pivotal although people's needs varied greatly as to the detail they wished for. Several people commented that they were unable retain all the verbal information given about the medicines but there were mixed views on potential usefulness of having written information.
- Experiences were in the most part of good care with effective and responsive symptom management but some people described poor experiences, where systems failed them and the knowledge of professionals seemed to be inadequate.
- When the medications were required the most common problems carers experienced were: delay in a health care professional (HCP) attending to administer medication (29%); knowledge of the person attending (24%) and deciding when to call for help (21%). Chart 2 shows the percentage of caregivers who experienced different problems.
- A high proportion of interviewees would consider extending their role as co-workers to undertaking administration of injectable medications to manage symptoms. The greatest drive to this was because of waiting for professional attendance and witnessing significant distress.

Thank You

A heartfelt and tremendous thank you to everyone who took part in this research. We appreciate how challenging thinking about this time of your life might have been. Your contribution is very much appreciated and we hope that you feel that it has been valued.

METHODS

This was a two stage study:

- Stage one postal questionnaire
- Stage interviews with a sample from those who returned the questionnaire.

We developed the questionnaire and the topics to discuss in the interview with the help of people who had previously been in this situation.

100 people were identified from the hospice notes and invited to complete the questionnaire and 38 people returned it.

14 people were then interviewed to give more in depth insights into what happened for them.

Chart 1: Were there any benefits to having anticipatory medications?

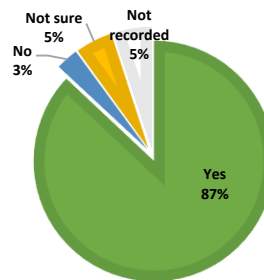
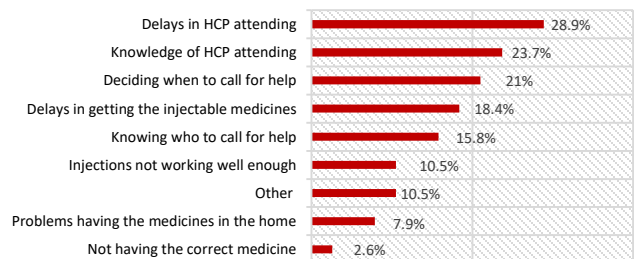


Chart 2: Percentage of caregivers who reported having encountered the following problems



WHAT HAS HAPPENED

We have shared the findings with health professionals at local, national and international conferences and have sent our paper to a journal for publishing.

We are developing a new leaflet for use locally

We have used the findings in training for nurses and doctors, emphasising:

- the importance of communication and explanations
- that potential misunderstandings and anxieties, including those about the future, should be given adequate time in open conversations
- that family need more support in knowing when to ask for help and in reducing the burden of responsibility for these medications.