

Carers needs assessment: analysis of the findings report and areas for action

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Background

A carer's needs assessment was developed to explore the needs of carers attending Yorkhill hospital with their children. It was recognised that Out Patients Department within Yorkhill was a starting point to consider exploring what carers need in a children's hospital setting. Yorkhill Hospital is a unique setting whereby families often attend regularly and over a prolonged period of time during a child's lifespan. The opportunity to identify the carers' role, consider their needs, and consider support requirements, and to respond to this, is also unique.

The recent Carers Information Strategy clearly provides the reasons as to why the NHS are key in supporting carers in their caring role. It states "NHSGCC recognises the fundamental importance of unpaid care to our whole range of services and objectives, and the impact which caring can have on carers' own health, wellbeing and economic status". The strategy identifies that carers should be treated as partners and that it is important to identify those who have caring responsibilities, understand their needs, support and involve them as individuals in their caring role.

The Scottish Government estimates there to be an excess of 650,000 carers in Scotland that provide vital care to a family member, friend or neighbour. They also identify that many carers are "hidden carers" who may not be identified as carers, might not identify themselves as carers and therefore are not supported by services.

The focus of this project was primarily not young carers; however it must be acknowledged that their role is relevant and has been identified.

The Scottish Government estimate that there are over 100,000 young carers in Scotland, under 18 years of age who provide care to a parent, sibling, grandparent or other relative who is disabled, has chronic illness, mental health or addiction problems. It states "young carers are often "hidden carers" who carry out significant or substantial caring tasks that would normally be associated with an adult."¹

Rationale

Caring can have an adverse impact on the mental, emotional and physical health of carers and without appropriate and timely support and information, carers can be at real risk of experiencing crisis. Parents are often an unrecognised group of carers as they see their role firstly as a parent and often, they themselves do not recognise that they are carers. It must be acknowledged that within Yorkhill hospital setting, families will repeatedly attend for care and treatment particularly when children have long term conditions. In order to understand their needs and to further identify the role of acute in supporting carers, the carer's needs assessment was developed.

¹ Scottish Government www.Scotland.gov.uk/Topics/Health/care/Strategy

Aim

The aim of the carer's needs assessments was to identify and prioritise support issues to enable a programme to be developed to meet the carer's needs.

A questionnaire was developed to consider and explore the needs of parent carers attending the Out Patients department at Yorkhill hospital. Out Patients was chosen as it was recognised that parents of children with long term conditions attend for clinic appointments and that whilst they were waiting, would be able to take some time to answer the questions and reflect on their own situation as a carer. Two afternoon sessions were identified on 26th of January and 27th of January, 2011. These sessions were chosen to fit with the diaries of the staff who were conducting the questionnaires. At this point consideration had been given to the possibility of having to revisit and arrange future sessions if the response rate had not been adequate.

Methodology

The questionnaires were agreed with a range of staff including Family Support and Information Centre and a Patient Information Centre staff member who has a specific carer's support role. The semi structured interviews were conducted by two staff with adults in the out patients waiting areas. See appendix 1 for a sample questionnaire.

The questions and results were uploaded into an XL sheet and the responses have been themed to allow grouping the responses particularly in relation to the comments from the different parts of the questionnaires. Theming has been used to describe how information is organised and sorted into common headings where common concepts and issues have been identified in comments from the carers.

Results

Forty questionnaires have been fully completed and three others have been partially completed. The three that have been partially completed stated that they have previously been a carer and they have provided very useful information in their responses and for this reason their responses are included. The analysis is based on the total number of 43 responses.

Question 1 - Do you help to care for someone?

There were 39 respondents who were carers that helped to care for someone. Three respondents were no longer in a caring role and one identified that they will be a carer in the future.

Question 2 – **Can you identify yourself as a carer?**

24 out of 43, or 56% of the carers are what the Scottish Government term hidden carers as they do not identify themselves as a carer even although they had answered yes that they are a carer, and their answers to the remaining questions would classify them as a carer. A hidden carer is someone who would potentially not be aware of services that are in place to support them and who may be more at risk of a crisis situation due to a lack of support and information.

Question 3 – **Do you have other children who may help you to care for someone?**

17 respondents or 39% of carers identified that they had a child or children who helped them to care.

Comments ranged from:

- Every day was commented by 7 respondents
- When home was commented by 2 respondents
- Sometimes was commented by 1 respondent
- All the family help out was commented by 1 respondent
- Sister was commented by 2 respondents
- Cousin was commented by 1 respondent
- In the past was commented by 1 respondent.

Although respondents were not asked the age or ages of children who helped to care below are the comments from the respondents:

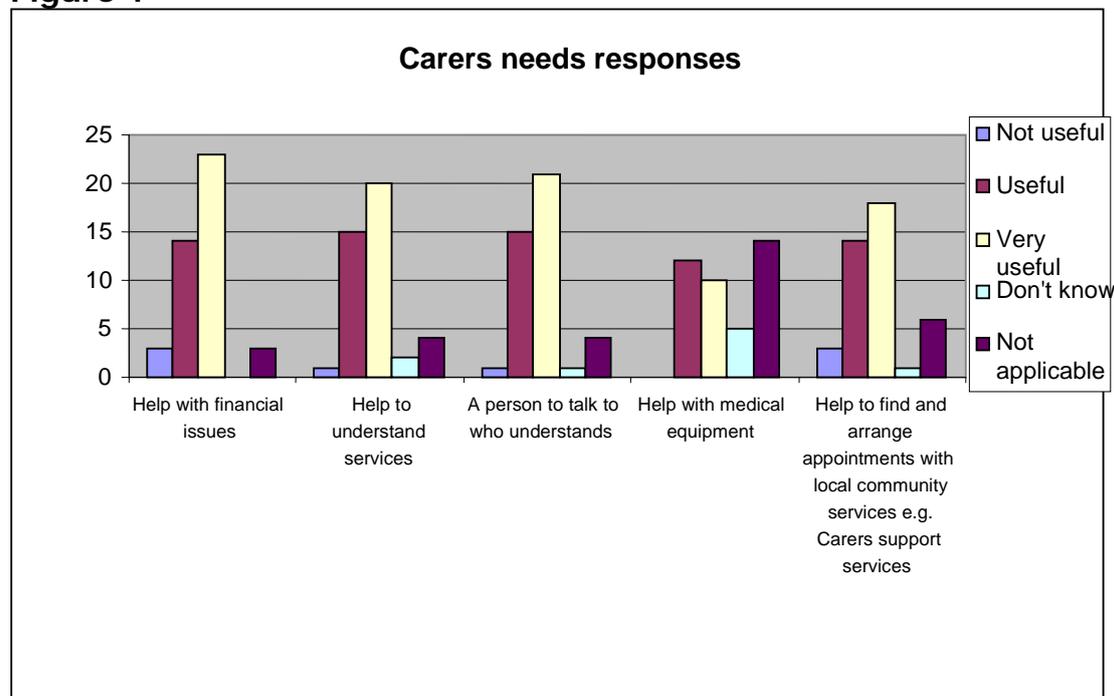
- Age 3
- Age 8 helps everyday
- Age 9 helps when home
- Age 10
- Age 12 whenever she can

Interestingly of the 17 respondents who had identified children help them to care, 10 had not identified themselves as a carer. This means that these families do not recognise the term or their role as a carer and therefore may not get the support or help that is available to them in their caring role.

The remaining questions asked specifically about services whilst visiting the hospital and a breakdown of the responses is in figure 1 below.

The table below demonstrates the responses when asked about which services would be useful when visiting hospital

Figure 1



Question 4 – **Is there anything else that would be helpful?**

Answers have been collated and themed to allow ease of reading below. These comments also help to aid an understanding the carers needs:

- 1) **Future assistance** was identified by 6 respondents. Their comments identify that they may need more help in the future as they are unaware of what may happen.
- 2) **Advice and information** has been identified by a number of respondents who identify that more information about long term conditions and information about other services from the hospital would be useful.
- 3) **Unaware what is available** have been comments from 3 respondents who identify that it is important to know what is available.
- 4) **Ok for now** has been commented by 2 respondents who identify that they manage at the minute but that this may change.
- 5) **Previous carers** were highlighted in comments and one specifically identified that they had a dual caring role and cared for more than one person.

- 6) **Death** was highlighted in comments where it was identified that knowing what to do in the event of a death was useful and more useful for a carer who is on their own.
- 7) **Carers** information was identified in respondents comments who identify that they have never had carers information passed on in the hospital and that there is lots of help about medical aspects but not so much about practical aspects of caring.
- 8) **Financial issues** were identified in ten comments, further highlighting the need for help with financial issues. Comments have a similar theme in that more advice and information given at the right time, preferably when children are young or diagnosed, would be very useful
- 9) **Child care** was identified as something that would be useful when attending the hospital with other children.
- 10) **Communication** was identified as something that could be improved between consultants and different departments.
- 11) **Other comments**
 - o "We get a lot of help from staff, especially with medical equipment."
 - o "Text on mobile about appointments is really useful."
 - o "Thank you very much for asking me."

Summary

This report provides an overview or snapshot of carers needs taken over 2 afternoon clinic sessions at outpatients only. These questionnaires have not been carried out in any other departments of the hospital.

Help with financial issues or benefits and specialist money advice was highlighted as the top carers need with 23 respondents identifying it as very useful and 14 as useful. The issue of poverty remains significant for families accessing services at Yorkhill Hospital.

A person to talk to who understands the challenges of being a carer was the next most important with 21 respondents identifying this as very useful and 15 as useful.

Significant numbers of adult carers were hidden carers with a number of children also providing care whilst remaining hidden carers. The Carers strategy requires NHS staff to identify carers and as a minimum signpost to dedicated support services for patients / carers.

Help to find and arrange appointments within local communities' e.g carers support services was highlighted as a significant need with 18 respondents identifying this as very useful and 14 as useful.

Links to carer's services and in reach for carers services would be useful in supporting the needs of carers and must be acknowledged.

Medical equipment was highlighted as something that parents / carers had a lot of support with whilst visiting the hospital. Their comments were very positive regarding medical equipment.

Proposed areas of action to meet Carers needs

It is important that NHSGGC address the carers needs identified through this assessment and consider:

- Explore the process for identification of carers within Yorkhill.
- Support for those who will be identified as carers, as close to diagnosis as possible.
- Provide information for both adults and children who are identified as carers to access local support e.g from Carers services / support groups.
- Increase availability of the appropriate support and information in order for them to carry out and maintain their caring role.
- Explore the potential for in-reach for access to carer's information and support can be achieved through a bid to the carer's information strategy group.
- Consider if in reach for financial issues e.g. DLA, fuel poverty and other financial information with a view of maximising income can be provided.

The development of a detailed action plan would be beneficial. The action plan should be progressed via the Health Improvement Steering Group for Women and Children's or the Better Together, Quality and Monitoring group.