

Scoping the Assessment Needs of Young Carers of Adults with a Long Term Condition

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Abstract

The numbers of people living with a long term condition are increasing. People with long term conditions appear in a variety of health settings. Many of these may have young families and be reliant on them for help. The United Kingdom government policy recognises the contribution of carers and the need for assessment in their own right. The aim of this research was to bridge the gap between adult and child services by developing an assessment tool for adult nurses to use when working with a family where a young person is involved in the care of an adult with a long term condition. The study utilised a qualitative approach gathering data by means of three focus groups and developing results from thematic analysis to formulate an assessment tool. The findings identified that health professionals did not always know about young carers in their catchment or case load area, services were usually focused on the person cared for and explanations about the long term condition needed to be clearer and age specific. Cross-cultural applicability of the assessment tool has also been considered in terms of adaptability to other settings. The conclusions reached were that using an assessment tool to assess young carer input and needs when the person cared for comes into contact with acute services could help to create greater awareness of young carers and their needs.

Keywords: Long term condition; Young carer; Assessment tool

Introduction

The numbers of people with a long term condition are rising with more than 15 million people suffering health problems which are incurable in England alone [1]. People with long term conditions appear in a variety of healthcare settings. Young people are often involved in helping to care for an adult with a long term condition. The United Kingdom (UK) government has made a commitment to protect children and young people from inappropriate caring. However, a key problem identified by health and social care practitioners, carer support projects and a recent media survey is the invisibility of carers in general and young carers in particular. Young carers' contributions to caring for an adult often go unnoticed and therefore their needs are, similarly, overlooked. This paper presents a pilot research project whose aim was to bridge the gap between adult and child services when considering caring for someone with a long term condition. The focus of this research is on identifying how young carer's needs, can be recognised within adult assessment processes by addressing the question:

"How can young carers needs be included in the assessment of an adult with a long term condition?"

The reasons for these are complex. Health professionals need to adopt a holistic approach that co-ordinates assessment of the adult with the long term condition within the needs of the whole family. This is especially the case within adult nursing where assessments tend to be focused on the adult with the long term condition. Some assessment tools are available which focus on specific carer needs, but these are mostly too large to incorporate into routine nursing assessment processes.

This paper will explain the methodology used to address the research question and discuss the results concluding with some implications for practice

Literature Review

The numbers of young carers are grossly underestimated due to their lack of visibility. Census figures suggest that there are a total of 175,000 carers in the UK, but the true number is closer to 700,000 [2]. Although government policy has committed to protect children and young people

in the UK from inappropriate caring and to support them to achieve the outcomes set out in *Every Child Matters* [3] services for children who are caring have still not greatly improved, despite increased funding, because of a lack of coherent assessment strategies [4]. In other parts of the developed and developing world, for example Australia, USA and sub-saharan Africa, recognition of the existence and significant responsibilities of young carers vary widely, and tailored support from government and other agencies even more so [5]. Studies exploring the experiences of young carers in the UK suggest that professionals need to be cognisant of child carers' needs and expertise [6-8]. Children are engaged in caring activities often carried out by professionals as well as more fundamental tasks such as washing and dressing. Research has also shown that when children are regularly and routinely caring their development is affected in terms of physical and mental wellbeing, and social and educational opportunities [9]. However, unless young carers' needs are assessed such issues will remain hidden. Young carers should have access to the social opportunities of their peers, but many do not because of their caring obligations [10]. This would appear to be a common experience for carers globally irrespective of their culture or welfare support system [5].

The professional group responsible for managing people with long term health conditions in the UK are community matrons. The community matron role in the UK has taken on many of the responsibilities for the co-ordination and implementation of home based care, but many community matrons also struggle with the case load numbers they are expected to manage [11]. It might be assumed that this group would have knowledge about families where a child

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is caring for someone with a long term condition. Nevertheless, the community matron's primary focus is usually on the person with the long term condition [12]. However, it is recognised that using a whole family approach can help to increase the support for young carers in particular [13]. The idea for this study grew from awareness of these factors, and the gaps in health and social care professionals assessing the needs of young carers in particular.

Methodology

The project aims were to bridge the gap between adult and child services by developing an assessment tool for adult nurses to use when working with a family where a young person is involved in the care of an adult with a long term health condition. People with long term conditions are predominantly cared for in the community in the UK only accessing hospital services during an acute relapse. The research was set in the community because it is in the community, at home, that young carers' lives are most disrupted, hence the focus on chronic conditions where disruption to adult health needs occurs over time [14]. The objectives of the project were:

- To map current practice of those working with people with long term conditions
- To work with community matrons to develop an appropriate assessment tool for assessing young carers' care obligations and their potential needs, for adult nurses to use in any setting where the person cared for presents
- To draft a questionnaire to evaluate the use of the tool

Ethical approval via the National Research Ethics Service was gained prior to commencement of the study. As the study subject revolved around people's experiences a qualitative approach was utilised. Qualitative research focuses on situations, the people involved in them and the activities carried out, using interpretive methods to make sense of these [15,16].

Sample

In order to map current practice, community matron participants, or those fulfilling an equivalent role, were recruited purposively via existing University practice networks from different regions in the county. 'Purposive' means recruiting and organising participants according to study purposes thereby increasing efficiency [17,18]. Those expressing interest in joining the research were given a research information sheet and were entered into the study on return of a signed consent form. The final sample size was a total of 12 participants of which 5 were community matrons and the other 7 were equivalent roles.

Data collection

Three focus groups were formed from the 12 participants and the focus groups were held twice with each group. The focus group sessions were an hour long, audio recorded and transcribed. The first focus group meeting considered the following questions in order to map current practice:

- How do you currently assess the needs of a client with a long term condition?
- How is a family assessment made?
- Where do you see young carers in these processes?
- Is anything further needed?

The second focus group meeting was used to identify assessment priorities which were then written into the assessment tool.

Analysis

The results were analysed using thematic analysis. Thematic analysis was chosen because it allows the researchers to group information through making sense of patterns in the data [19]. By working inductively with the data further questions were developed. This involved the two researchers reading the transcription for emerging themes independently and then meeting to discuss them. Disagreement was overcome by returning to the data transcripts and reassessing the categories for corroboration in the words used. The resulting themes informed the questions posed at the second focus group.

Development of assessment tool

The young carers' assessment tool was developed from the priorities identified through the second focus groups. The resulting assessment tool (Table 1(Included as supplementary data)) was shared with all the participants for verification and then shared with a young carer group for scrutiny and refined further. One of the key points identified by the young carers group was a lack of child friendly books, or information sheets, about different long term conditions. Finally, a conference was held for local health and social care practitioners with workshops showcasing the tool. The tool was also presented again at an International conference to delegates from across the world.

Results

Focus groups results

The focus group discussions produced some rich data about the relationships between health professionals and those they cared for, but also indicated gaps in provision in relation to a limited focus on carers needs. The themes that emerged from the focus groups included:

- Carers' role and relationship
- What carers do
- Carers' perceptions of the condition and their maturity to understand it
- Carer strain
- Risk assessment – how is vulnerability identified
- Cultural context
- Support needs
- Assessment and review of outcomes

Relationships between the carer, the person being cared for and the health and social care team were key to sustaining carers. However, it was also recognised that young carers had many anxieties which required additional emotional support. The results identified that the assessment tool needed to consider the type of caring undertaken, how young carers were coping, their cultural needs, how their life and schooling were affected and emotional aspects of their need and support.

Assessment tool development

When considering developing a tool it was also important to review the outcomes of any referrals or support. The resulting assessment tool included the following domains:

- How many people is the young carer caring for
- Type of caring
- Whether the young carer was solely responsible for this care

- Cultural context and needs
- Whether the patient assessment had been explained to the young carer in terms they can understand
- Whether the young carer's life or schooling was being affected
- Does the young carer do anything other than caring and school activity
- Sources of information or services offered
- Are the young carer's tasks manageable and if not what do they need
- What extra support has been requested for the young carer
- What other agencies are involved with the young carer
- Has the young carer had a carers assessment
- What is the young carer's support network if the patient gets worse
- Was the young carer present when the form was completed
- Outcomes review (e.g follow up of referrals, update of any situational changes)

(Table 1 (Included as supplementary data) for the assessment tool)

When the assessment tool was reviewed by the participants and the young carer group their comments were about making the questions clearer in order to capture correct details. For instance, identifying the composition of the household and how many people were being cared for, including more tick box options relating to the type of care and involvement of other agencies and inclusion of a numbered scale to identify whether the carer's tasks were manageable. The assessment tool was refined further in response to this feedback. A questionnaire to evaluate the use of the assessment tool was also developed which asked:

- How useful the tool was to community nursing practice
- What if any change needed to be made
- How the tool could be disseminated further in nursing practice

Discussion

Caring roles and tasks may start from a close relationship with the recipient who is often a family member or a friend. Becoming a carer can be seen as the only possible solution to managing a new or difficult situation, and in some cultures caring is viewed as an expected duty [20]. Integration of care services is essential for the health management of people with long term conditions and lack of integration is a particular source of frustration for those caring for them [21]. The pilot study under discussion here suggested that ways of working and support services differed considerably within the range of locales involved. It could be argued that such diversity of provision makes it difficult to integrate services in ways which are meaningful and effective for people. This was particularly true where there were distinct cultural expectations linked to young people becoming carers. As identified within the literature, young carers were sometimes not visible to community matrons as attention was focused on the person with the long term condition. A further problem was that the assessment documentation used in community care and in the acute (hospital) sector usually remained within that sector, rather than being incorporated into community nursing paperwork thereby missing the opportunity to better integrate assessment results and include carers' needs in ongoing assessment and case management material.

Assessment tools are not only useful for assessing carers' needs, but can also provide vital intelligence on the appropriateness of proposed interventions for the person cared for [22]. It would seem appropriate to include everyone involved in a person's care in the assessment process, in order to demonstrate value for their contribution as well as gain a better understanding of their needs. This can help to build better relationships between families and health professionals [22]. Assessing needs from different perspectives can also reveal important information which is relevant, but which might otherwise be missed [23]. The results of the study reported here have suggested that young carers have additional emotional and development needs. Therefore, including these in assessment could help reveal important features which might be impacted by the caring role of the young carer, or which could impact upon the care given that otherwise might remain hidden until caring relationships break down.

Although the purpose for using assessment tools varied between the UK, Canada and Sweden their common focus was identifying carers' needs in order to improve services [22]. Nevertheless, within these projects carers appear to be a homogenous group with little differentiation of age related needs. Although the tools facilitated a more in-depth carer focused assessment they took longer to complete creating tensions in the care undertaken by professionals with most between 4 and 30 pages long. In contrast, the assessment tool developed from this study is intentionally short (a double sided page) and intended to be transferable between settings i.e to follow the patient, partly to remedy the situation described above. This is important for clinical practice where time is often at a premium and is a particular outcome of this study. Equally, refined clarity means that the assessment form can be understood by professionals and carers. This is important for gathering data about carers' needs and addressing them. The tool could be further adapted for wider cross-cultural applicability through consideration of the particular cultural interpretations of family and childhood as well as the welfare and care systems relevant to the context. The tool is sufficiently generic to allow such adaptation to take account of young carers' lives in other geographies without adding to the burden of practitioners completing it.

Limitations

The project was, however, limited. A key limitation was the size of this project, as this was conceived as a pilot study to identify how young carers' needs could be assessed as part of the assessment of the adult being cared for, to generate hypotheses about more effective approaches to integrated hospital - community case management that might enable development of a larger project to test findings and tools at a later date. Furthermore, the project was time limited in scope and thus it was only possible to involve young carers at one point in the process. Ideally a larger project might also consider varied ways of incorporating the voices of young carers into the development of tools and services designed to more appropriately meet their needs. Any future larger scale project should also consider a broader geographical remit than one UK county, and attempt to address this for international considerations.

Key Points

The key points from this study are that:

- There needs to be better integration of assessment of the person with the long term condition and the needs of the person caring for them, particularly young carers
- Young carers need to be given information about the long term condition in ways that they can understand

- The potential impact on the schooling and life activities of young carers needs to be recognised and supported more widely
- Assessment tools which are short and transferable between care settings can contribute to integrating assessment
- Further research is needed to replicate the study on a wider scale

Conclusions

This pilot study has identified key points of assessment for young carers caring for an adult with a long term condition. An assessment tool has been developed and disseminated to health professionals locally, nationally and internationally. There is an opportunity within acute areas of nursing to integrate assessment of young carers' needs within the assessment of the person with the long term condition. This can potentially help identify young carers more effectively. Such an integrated assessment also provides opportunity to discuss a young carer's understanding of the person's long term condition (within the boundaries of confidentiality) and family inclusion promoting a more holistic approach to assessment. The clinical implications of this are gaining a better understanding of patient and carer needs, ensuring that any proposed interventions are relevant and tailored to their needs, thereby promoting efficiency and concordance.

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