





How do we ensure that training and information support contributes to positive outcomes for carers?

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Executive Summary

This research aimed to gain an understanding of how training and information support contributes to positive outcomes for carers. It provided a range of information to answer specific questions such as:

- Do carers feel that their needs are identified appropriately at different stages of their journey?
- Does training contribute to the carer's outcomes?
- What are the barriers to carers engaging in training?

Key findings

- · Training plays a significant role in both enabling and empowering carers
- There are a number of points in the carer's journey where training can provide support such as: at diagnosis; where a condition deteriorates; or where other carers or family become involved
- There are a range of barriers that prevent attendance or reduce the potential impact of training
- The development of a relationship between the carer and those supporting them - either in statutory or non-statutory services - is significant in improving the effectiveness of the discussion and subsequent delivery of training for a
- The functions of training are varied but equally important, including:
 - Practical training that delivers hands-on skills such as first aid or moving and handling
 - Condition specific training to help carers and their families understand what is happening to their family member, such as for those with dementia, autism or head injury
 - Training that supports the wellbeing of the carer such as personal effectiveness, assertiveness or mindfulness
- Follow up after training is important to ensure that it has met the needs of the carer.

Recommendations

- Further work undertaken to identify ways to minimise barriers to training in each locality and also comparisons of factors such as age or location
- Key stakeholders are made aware of the importance of identifying carers so that their training needs can be discussed (General Practitioners, key service colleagues in health and social care, acute services.)
- That the wellbeing of carers is also considered in terms of training including mindfulness, assertiveness, managing stress etc
- Services recognise the importance to carers of a relationship to support them through the identification of training, accessing and attending sessions and also following up to review carer needs.

Introduction

A carer is defined as a person looking after another person (Scottish Government 2010).

This research focuses on informal carers in the South of Glasgow City, who look after a relative or friend and do not receive payment. Carers may include parents looking after a disabled child, a spouse caring for their husband or wife with dementia, a young carer who supports a household due to parental illness or someone looking after a person with a terminal illness. Carers arise in all parts of the City and from all social groups and their caring role can be of short duration or over many years.

Feedback from carers has identified the importance of training in supporting their role as a carer and also as a means of creating peer support networks for carers in similar circumstances. The question being asked within this research was: 'How do we ensure that training and information support contributes to positive outcomes for carers?

This was broken down into further questions to identify the carer's perceptions of training.

- Do carers feel that their needs are identified appropriately at different stages of their journey?
- Does training contribute to the carer's outcomes?
- What are the barriers to carers engaging in training?

Background Information and Literature Review

Glasgow City has established a *Partnership of Carers* which includes statutory and non-statutory services as well as carer representatives. A pathway has been agreed that supports the identification of carers at the earliest opportunity and also enables carers to step in and out of the pathway at various points, dependent on their needs. There is a Carers' Helpline, currently co-ordinated by a non-statutory service that is widely advertised and acts as a means of sign-posting carers to appropriate local agencies or providing general information for carers who may then choose to engage more fully with carer support services.

Carers are identified in a variety of other circumstances and locations. This may include at point of diagnosis, such as in the case of dementia or through a variety of professionals or circumstances including: visiting their General Practitioner; an admission to hospital; attendance at a health or social care appointment; or through contact with other services or agencies such as schools, third sector organisations or self identification. The intention is to offer support to carers at the earliest opportunity and to have a system that responds to changing needs that may occur due to the condition of the person they care for or the carer's individual circumstances.

The Carer Pathway supports early identification of carers and enables an assessment of need using an initial self-assessment mechanism, followed by a more detailed assessment and / or referral / signposting onto other services to support the carer.

For each carer, the agreed pathway is that an individual support plan is drawn up. Contributions to this may come from statutory or non statutory services and this plan

may include a range of support such as advocacy, information, income maximisation and also training.

Training to support carers can be identified at any part of the pathway and used in direct or indirect ways. This might include: training in the form of information - being taught to use a specific piece of equipment; to provide an understanding of the condition of the cared for person - such as in the case of dementia or autism; or to contribute to the health and wellbeing of the carer in order to support how they continue to care – mindfulness, assertiveness.

A review of the literature has identified estimates of the number of carers in Scotland. and a range of research undertaken to identify how training supports carers in undertaking their role, maintaining the caring relationship and also the barriers to engage in training.

The Scottish Health Survey (Scottish Government 2015b) highlights that around 17% of the population of Scotland class themselves as a carer – 759,000 people. It also notes that around 4% of the population of Scotland are providing over 35 hours of care per week. This equates to around 171,000 people in Scotland.

The Census in 2011 (National Records of Scotland 2014) identified that there were 53,914 people (9.09% of total population) who self-reported that they were carers in Glasgow City. Of this group, 17,110 people reported that they provided more than 50 hours of care per week, which is a high level of care provision. The Scottish Government consider the Census data to be an under-reporting of the extent of identified carers (Scottish Government 2015b) so this figure in Glasgow is likely to be even higher.

Carers provide a significant level of care and support to people in the community (Scottish Government 2015b). In the absence of the carer, or if there was a breakdown of the carer support, there is a risk that statutory or third sector community services or even hospital services would need to take on this role. (Scottish Government 2015a, Murray 2014, Roy & Gillespie 2011, Clarke 2001, Davis 2010, Silva et al 2013). Many carers provide significant levels of sophisticated care supporting physical and psychological needs of the cared for person. In many cases, carers are isolated and there is an impact on their own physical, mental, social and emotional health (Scottish Government 2015a & 2010, Silva et al 2013, Turner & Street 1999). There is significant evidence of the requirement for carers to be supported by the provision of training to increase knowledge, skills or understanding of a condition or practical requirement (Sahar et al 2003, Davis 2010, Edwards et al 2014, Toot et al 2013, Clarke 2001, Turner & Street 1999, Norman and Purdam 2013). This can take the form of skills-based training such as moving and handling, first aid or management of a specific aspect of an illness such as dealing with fits. Training can also be condition specific, where the aim is for the carer to better understand the condition and how it can be managed or training can support the carer through wider information, training to support their employment or to build their confidence (Scottish Government 2015a).

Davis (2010) notes the value of practical training through a third sector provider delivering information and awareness to carers which reduced risk of injury and promoted wellbeing of carers.

Leite Silva et al (2013) looked at the literature around the support needs of carers of older people living at home. They identified a number of themes including

professional support, effective communication, legal and financial support and a significant need around information and training. This training need included:

- A need to understand the diagnosis / condition
- Information on treatments including medication
- Services available and how to access these
- Practical skills to undertake care tasks or to use equipment
- Support for the carers own wellbeing

Murray (2014) in looking at carers of people with dementia highlighted impact on carers and the frustration and helplessness that carers may experience due to a lack of understanding of the condition.

Methods

Data Collection

The research questions were addressed using a semi-structured focus group that included carers from a range of backgrounds and experience. The criteria used to choose carers was:

- Adult carers over 18 years of age
- Completion of assessment including identification of training needs
- Completion of one or more training programmes to support their role as a carer

Invites were sent to a range of carers on behalf of the researcher by the local third sector carer support service in the South area of Glasgow City. Respondents included carers from both the South West and South East of the area. A total of 11 carers agreed to attend a single focus group. Options were to add further groups to this, but the depth of the data gathered in the main group provided a rich source of information allowing detailed exploration of the research questions.

Part of the structure of the focus group involved the use of an evaluation wheel (Higher Education Authority 2007, Evaluation Support Scotland - Website) which enabled the carers to identify their personal perspective against a series of outcome based statements which included (Appendix A):

- There have been barriers that have meant I didn't get the best out of training
- After I have attended training, I have been part of a discussion to update my training needs
- Training has helped me in my caring role
- I have the right support to maintain my role as a carer
- My Carer assessment process has identified my training needs as a Carer

This stimulated the discussion around the research questions.

Additional information was gathered using the training database held by the third sector organisation that hosts the training function on behalf of the South area. This included details of the range and numbers of courses offered, as well as actual attendance and the origins of the programme in terms of how the need has been identified. A further review was made of the evaluation of programmes exploring positive and negative comments raised across a range of training.

Data Analysis

The focus group was recorded with the permission of all parties and provided detail around key issues to answer the research questions.

Holloway (2005), and Pope and colleagues (2000), describe a content analysis approach by indexing information in its textual form and generating analytical categories and theoretical explanations. They describe inductive analysis – built gradually from the data and also deductive analysis – obtained at the beginning or part way through the analysis. May (2011) and Doucet and Mauthner (2008) highlight the challenge to the researcher in taking rich narrative from interviews or group discussions and identifying themes.

Doucet and Mauthner (2008) identify an approach around reading narrative data to understand four aspects including:

- the overall story and listener's response
- the "voice of I"
- an understanding of relationships within the data
- the social content of the information

Pope and colleagues (2000) suggest five steps of data analysis when looking at large volumes of transcribed data:

- a process of familiarisation
- identification of a thematic framework
- indexing
- charting
- mapping and interpretation

The risk of not following a structured framework such as this, is that findings will be anecdoetal, unreflective and descriptive information that is not focused on a coherent line of inquiry.

The recorded conversation was analysed using the approach identified by Pope (2000). The recording was reviewed using this framework and was partially transcribed to identify themes and to develop indices which helped to map data for interpretation.

Records of training were analysed to provide a summary of programmes offered across key areas of:

- Skills-based training for carers
- Condition / understanding activity
- Wellbeing activity

This identified numbers of programmes, places offered and also places taken up.

Ethics

There are a range of factors requiring ethical consideration within a research project. Ethical issues are considered to safeguard the rights, safety, dignity and wellbeing of people who are engaged in research. This includes staff, services users and other stakeholders (carers, relatives, others).

For NHS research, this will include questions around the selection of subjects (randomisation, inclusion / exclusion), whether the information gathered will be generalisable (development of new knowledge to be used in approaches across a wider group of individuals) and finally whether the information or process would impact or change the process of treatment or intervention.

NHS Greater Glasgow & Clyde uses a process that asks first for detail of the proposed project and then uses a questionnaire to ascertain whether the proposal is research and thus requires a detailed application for ethical approval, or audit / evaluation which does not require this process. The questionnaire is derived from the National Research and Ethics Service, which is part of the Health Research Authority. This guidance was revised in 2013. (HRA 2013) (http://www.hra.nhs.uk/research-community/before-you-apply/determine-whether-your-study-is-research/). An individual is assigned to support the process to consider the requirements for full ethical approval. (The questionnaire is available at http://www.hra-decisiontools.org.uk/research/)

For the purposes of this study, the process identified that full ethical approval was not required as it was defined as an evaluation / audit project.

Other ethical considerations are however required to ensure that participants are supported through the process and also to ensure that they understand that participation will not in any way impact on the care and support they or their family receive.

Each participant was invited to engage in the process. The invitation letter identified the nature of the research and also that the individual could withdraw at any time. At the beginning of the focus group, each participant who attended was asked to complete a consent form following a further discussion around the purpose of the research (Appendix B). The session was recorded and this was an implicit part of the consent process. The confidentiality of the recorded data and any transcription or other information was reinforced, including no inclusion of identifiable information in the reports being produced. Participants were told that at anytime they could withdraw from the session or ask for the recording to be stopped. On two occasions, participants became upset when they were explaining their personal circumstances, but were happy for the group and the recording to progress.

It was explained that the outcome of the research will be shared with participants with copies of the summary being shared within the Carer Centres as well as the link for the research report being placed in the Carer Centre Newsletter.

Results and Findings

The focus group consisted of 11 individuals from a range of ages and caring backgrounds. All were female and aged between 18-64 years. The length of time they had been caring was also varied. Some had been caring for as little as 6 months, whilst others identified that they had undertaken the role for 20 years. The average length of time was 9.7 years (median 9 years). All of the group classed themselves as full time carers with one also noting that they cared for more than one person (mother and son).

There were some commonalities about the reason for their role as a carer. Some in the group looked after an older person with dementia, others cared for a person with a significant head injury and the others cared for a younger person with autism or a physical disability.

An evaluation wheel with defined outcome statements was used to initiate the focus group and to identify an understanding around how the carers had been involved in identifying training to support their role, if they considered any barriers to engaging in training and also to understand how training helped them. All carers strongly agreed that training had helped them in their carer role. Similarly, all carers felt that the carer assessment process had helped them to identify their needs. This was explained further in the group by noting that the assessment gave an overview of the issues, but more detailed discussion within the local carer centre provided the opportunity to choose the programme most suited to their needs. In terms of barriers to engaging in training, there was a mixed response, with some suggesting that there were barriers and others saying that there were not. Those reporting fewer barriers suggested that support received reduced potential barriers in a number of ways. Most participants reported feeling fully involved in on-going updates of their training needs. Further discussion noted ways they could be better supported.

The development of a relationship to support the carer role emerged as a theme from the focus group discussions. Although there were some very practical issues that an initial assessment or signposting can offer — such as income maximisation, information, advice — the discussion highlighted the value of someone having time to spend with the carer to understand their circumstances and to get to know them and their needs. This appeared to support the approach of the established Carer pathway which aims to refer carers quickly, to the most appropriate resource. The Carer Centre, currently undertakes this role with a Training Co-ordinator and local carer support workers spending more detailed time discussing the most appropriate training and most effective means of delivering this.

Carers identified a number of issues that were important to them, that were associated with the support offered at various stages, but appeared to be particularly important as training needs were identified, delivered and reviewed. The carers reinforced on a number of occasions themes such as:

- A carer's right to be listened to and heard
- For others (such as professionals, family and friends) to have an understanding of ever changing needs due to circumstances
- A need to be seen and treated as an individual
- Knowing that there is someone who genuinely cares
- The importance of the role that General Practitioners play in identifying carers and supporting them

The group identified other themes that carers felt were important in relation to training provision around what assisted them in accessing training, getting the best out of the training and also reducing any barriers to engaging in training. Examples of this included:

- Transport not always required but occasions where it would ensure that the carer attended on time and also then was relaxed enough to get the best out of the training event.
- Flexibility training provided at different times to meet needs of those who
 may have school age children or working partners.
- Opportunity to repeat things if the carer was unable to maximise the benefit of a particular training – also recognising that some carers have different learning needs.

In many circumstances, there are barriers to engaging or attending activities. The analysis of training information highlighted a number of individuals who did not attend events and on follow up there were a number of reasons identified. The focus group reinforced this by noting a range of issues in their experience that had meant they hadn't been able to attend training. This included circumstances around the person they cared for and also personal circumstances. Examples identified included:

- Personal illness or illness of the cared for eg physical illness or having not slept the night before because they had to look after the cared for person.
- A change of circumstances around the cared for person not related to illness

 eg where behaviour exhibited means that they cannot leave the cared for person
- Confidence having agreed to attend a group, the carer thinking that they are
 not comfortable with engaging. This was noted as being minimised with
 appropriate information beforehand or knowing other people who might be
 attending, or knowing that they would see a familiar face at the training staff
 member.

A further theme identified was around circumstances that impact on the effectiveness of training for carers. Some of these issues were from the perspective of the carer and their preparation or mind set so that they gained from the training, whilst others were practical issues that may have ensured a better outcome.

- Carer not having access to sufficient information about the venue, times, programme and any requirements
- Travel to a venue meaning they are stressed before the training starts
- Concern about the cared for person who may have some respite in place so that the carer can attend training
- Needing more time to understand things because of different needs or backgrounds of each carer, occasions where some components of training not covered or rushed at the end of the training.
- Some courses have too much content and may need more time to deliver what is required.

The benefits of training were reinforced through the focus group discussions in a range of themes. This included;

- Involvement of family and siblings in training. This helped to ensure a wider understanding of the needs of the cared for, especially if family and siblings have a role to care for that person. Carers suggested that as a minimum it gave others an awareness of what the carer needs to deal with.
- Carers felt that they could cope better because they understood a condition
 and were better able to deal with their own frustrations. Examples of this
 were around confusion as part of dementia and also the behaviours exhibited
 by children with autism. "I didn't know my boy anymore. The training helped
 me and my family understand that he wasn't just being naughty".

Key Findings

- Training plays a significant role in both enabling and empowering carers
- There are a number of points in the carer's journey where training can provide support such as: at diagnosis; where a condition deteriorates; or where other carers or family become involved

- There are a range of barriers that prevent attendance or reduce the potential impact of training
- The development of a relationship between the carer and those supporting them - either in statutory or non-statutory services - is significant in improving the effectiveness of the discussion and subsequent delivery of training for a carer
- The functions of training are varied but equally important, including:
 - Practical training that delivers hands-on skills such as first aid or moving and handling
 - Condition specific training to help carers and their families understand what is happening to their family member, such as for those with dementia, autism or head injury
 - Training that supports the wellbeing of the carer such as personal effectiveness, assertiveness or mindfulness
- Follow up after training is important to ensure that it has met the needs of the carer.

Knowledge Exchange

The Glasgow City Carer Partnership provides an opportunity for further discussion of the findings of this research. This complements existing work undertaken on an overall evaluation of the needs of carers and how services are delivered now and in the future.

Carers are also involved in this partnership and may be willing to share the findings with separate carer reference groups.

A summary sheet noting the research and its findings will also be made available to the carers who took part in the research.

Discussion / Conclusions

This project explored the feelings and experience of a range of unpaid / informal carers in relation to their engagement and involvement in training to support their role as a carer. Further work will be required to provide a comparator with factors such as gender, geographical location or age.

Although all of the carers involved in the research were female, 14% of the registered carer population who were involved in training in the area surveyed, are males. Further research might suggest that there may be gender differences in the experience of carers in relation to training.

This report focussed on one of three localities in Glasgow City. Further work may elicit differences across localities.

Carers were very supportive of non-statutory services, as they felt that these services had more time to spend with them to better understand the context of their needs. Their experience of statutory services in relation to training appeared to be that this was short term as they were referred for training to non-statutory services as part of the agreed carer pathway. The short-term nature of that engagement meant that they didn't get to know people very well in statutory services and that services didn't really get to understand their needs in relation to training. This finding however is supportive of the carer pathway in that referrals for training appeared to be made

quickly to the appropriate service. Carers also felt that initial needs identified may change or develop as the discussion with services begins to better understand the individual's circumstances, family dynamics and personal needs of the carer. This reinforced the value that the carers expressed around the development of the relationship between carer and service to identify more effective responses.

The follow up to review the delivery of the outcomes for the carer was seen as important to ensure that the needs had been effectively met and if not, that there was an alternative way of delivering this. The importance of the dialogue between the carer, training co-ordinator, training provider and the worker responsible for the outcome based support plan appeared to be critical.

Although the carers involved in this research appeared to have limited barriers to attending training, they were aware of circumstances that prevented others from attending. One key issue was around the confidence of a carer to engage in training with either a group of people they had never met or where they had not been involved in any training activities for many years. This further reinforced the value that the carers placed on having a relationship with a service where they felt they could get support to work through these concerns. Further work would be useful to explore wider barriers to training in more detail and any service responses that could be put in place to support this.

There are a number of potential recommendations to improve the dialogue with carers and also the opportunity to further improve the effectiveness of training for carers, along with additional areas for research. This report will be shared with partners in the Carers Partnership to identify how these may be taken forward as part of a wider review / evaluation of carer services and support.

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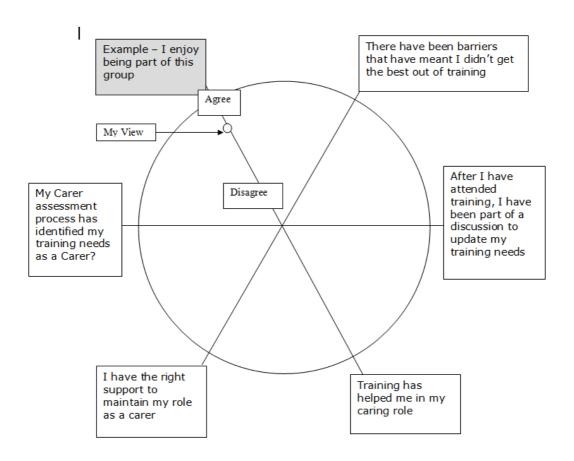
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Appendix A – Evaluation Wheel

Evaluation Wheel



Appendix B – Consent Form

My name is XXXXXX. I am a planner in the NHS and have a special interest in Carers and the support we can offer across health, social care and voluntary services.

I am undertaking some research that looks at the views of Carers around training.

I am interested in your views about how your needs have been identified and if the training has helped you in your caring role. I hope to use this information to develop better ways of responding to Carer's needs in the future.

I would like to join your group for a short time for a discussion about Carer training. To help me to pick up on all of your views, I would like to record the discussion. Any information you provide will be anonymised and will be kept confidentially until the report is written, after which the information will be destroyed. The discussion will not impact on any of the services you receive.

I would be grateful if you could complete and sign the information below which gives your consent to take part in the group discussion.

Thank you for taking the time to consider being part of this research. If you need any more details about the research, feel free to contact me on 0141 XXX XXX

Consent Form:

I agree to take part in the group discussion around Carer training as part of a research project. I understand that the discussion will be recorded so that the researcher is able to pull together key issues and to use this to inform the report. I understand that the information will be treated confidentially and that all references will be anonymous.

Name (Bloo	ck Capital	s)			_	
Signature :						
Date :						
Additional	Informati	on Rec	quired			
Carer :						
Age	0-18		18-64 □	65+ □		
Gender	Male		Female □			
How long h	ave you b	een a (Carer?		_	
How many	hours a w	eek do	you act as a Ca	rer? Less than 10	10-30 hours	Full time

Thank you for your help with this project.