

**The Impact of the Cornwall Carer Support Workers' Service on
Four GP Practices: Follow Up at 18 Months**

A Report for Cornwall Rural Community Council

Dr Jenny Morris
Cornwall Health Research Unit
Penhaligon Building
Trevenson Lane
Pool
Cornwall TR15 3RG

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Summary

The aim of this study was to investigate the extent to which systems and procedures instigated by four carer support workers have been maintained by the practice carers' contacts in four GP practices in Cornwall. The study took place 18 months following the departure of the carer support workers from the four practices.

Information was collected from the four practice carers' contacts and a random sample of five carers from each practice. Questionnaires were designed to collect information from the practice carers' contacts and the carers. The questionnaire for the practice carers' contacts focused primarily on roles and responsibilities; and that for the carers on identification of the practice carers' contact, provision of information and support, the carers' perception of the role of the practice carers' contact, and the view of the carers regarding how services for carers might be improved within the practices. Data were collected by interview.

The results indicated that not all the identified roles of the carer support worker were being maintained by the practice carers' contacts; this was particularly relevant in the case of maintaining databases. It was also clear that in some cases, the practice carers' contacts felt the additional work was a burden on top of their existing workload. In general, the carers interviewed thought highly of the services provided. However, 12 of the 20 interviewed felt that the practice should employ a person specifically for the role of carer support worker; and three of the carers from one practice did not know who the identified practice carers' contact was at their practice.

The results are discussed in the context of the methodological limitations of the study and some recommendations put forward with regard identifying what is required of the role of the practice carers' contact, and the need to consider employing an individual specifically for the role.

Background

It has long been recognised that the support for carers offered by primary health care practitioners is inadequate. In response to this, the secretary of the Launceston branch of the Carers National Association orchestrated a meeting between senior managers from the Cornwall and Isles of Scilly Health Authority, and Cornwall Social Services to discuss the possibility of funding a carer support worker at Launceston medical centre. This meeting took place in January 1996. The importance of providing this service was recognised by the Health Authority who funded five part-time carer support workers. It was agreed that at county level the Cornwall Rural Community Council (CRCC) should manage the implementation and outcome of providing this service; with a multi-agent project steering committee overseeing and monitoring the service. Membership of the steering committee included carers, representatives from the Cornwall and Isles of Scilly Health Authority, GPs and primary health care teams, Cornwall Social Services and the CRCC. Locally the service was overseen and monitored by a practice advisory committee for each of the five participating GP practices.

The five GP practices were selected to ensure representation throughout Cornwall. These were Constantine surgery (two GPs, approximately 3,500 patients), Gunnislake (three GPs, approximately 6,500 patients), Launceston Health Centre (six GPs, approximately 14,000 patients), Sunnyside surgery at Penzance (four GPs, approximately 7,000 patients), and Mullion Health Centre (three GPs, approximately 5,200 patients). Each practice had the services of a carer support worker for a period of two years which was considered a sufficient period to change the practice culture, and to set up appropriate systems for continuing the programme of support established by the carer support workers. Training of the carer support workers was the responsibility of the Carer Co-ordinator employed by the CRCC. The objectives identified prior to implementation of the service in July 1996 were as follows:

- a) To provide a resource through which GP practices and primary health care teams could both identify carers and support their patients who had caring roles.
- b) To encourage carers to become actively involved in the project development to ensure that the project evolved in a way which satisfied their needs.

- c) To improve accessibility to information, advice, counselling, support and assessment for all carers.
- d) To continue to forge new links and improve communication channels between statutory and voluntary organisations, and to facilitate the dissemination of information on existing, and new, services to carers.
- e) To facilitate the development (or modification) of existing community care resources for carers in order to meet unmet needs, in particular for carers who may have special requirements, for example, because of their youth, ethnicity or lifestyle.
- f) To ensure that Social Services, GPs and PHCTs were aware, and had better knowledge of the needs of carers. To acknowledge carers' expertise and competence and demonstrate a willingness to regard them as partners in the caring process.

(Source: Rabett, P. Cornwall Carers Support Workers Project. 1998)

While these objectives were applicable across all the practices, it was recognised that the methods utilised within each practice would vary according to local requirements. The tasks associated with the role of the carer support worker were to:

- a) Identify carers and compile a register.
- b) Set up a system to alert GPs to which patients are carers.
- c) Develop a system to allow support for carers to be integrated into the workload of the practice.
- d) Disseminate relevant information and advice to carers.
- e) Identify carers and their needs at GP practice level and make referrals as necessary.

(Source: Rabett, P. Cornwall Carers Support Workers Project. 1998)

The service has now been implemented and one phase completed with four of the five carer support workers initially employed moving on to new practices. Due to the very large practice population in Launceston, the carer support worker is still in place at this health centre. Whilst the service was monitored throughout the two years of implementation, the project steering committee considered it appropriate to evaluate more systematically the impact of the service on the practices involved.

The aim of this study was to investigate the extent to which the systems and procedures instigated by the carer support workers have been maintained by identified Practice Carers' Contacts (PCCs) within the four practices 18 months following the departure of the original carer support workers.

Methods

Design

The design of the project was determined by the timing of the evaluation, which began a year after completion of the service implementation, and also the funds available. A post-intervention without controls was the design utilised.

Sample

Staff at each practice responsible for the support of carers (the PCCs) were invited to take part in the study by the Carer Support Co-ordinator at the CRCC. In addition, information was collected from a random sample of five carers from each practice; this number was based on logistical reasons associated with the timing and funding of the project. Each practice manager provided a list of names and addresses of 10 carers to the research team; 10 names were provided for each practice to allow for leeway should some carers not wish to take part. Interviews took place in the carers' homes and were undertaken by the research assistant (female) who made contact with the carers to explain the nature of the project and to arrange a time and date for the interviews.

Data Collection

Two questionnaires were designed for the study. One for the PCC at each practice, and one for the carers. Where possible, closed questions were designed, with open-ended questions being used where it was necessary to obtain supplementary information. Questions used in a questionnaire developed for carers during the implementation of the carer support worker service were included to enable comparisons to be made by the CRCC if required. Other questions were included relevant to the tasks identified for the PCC (see p.5). The final versions of the questionnaires were approved by the Carer Support Co-ordinator at the CRCC. The questionnaires are included as the appendix to this report.

Data Analysis

Data from the questionnaires were analysed using the Microsoft Access database. Data from the PCCs' questionnaire were summarised for each PCC separately; and the data from the carers were analysed by practice and for the total sample.

Results

Roles and Responsibilities of the PCCs

The results relating to the information collected from the four PCCs are shown in Table 1. As can be seen, there were major differences in the roles held by these four people (the questionnaire in the appendix provides full information about the questions asked). At the Mullion practice, the PCC was a volunteer working for the carer support group and not employed by the practice at all (at least one nurse from the practice, however, attended the carer support meetings and outings). In the absence of the PCC, the nominated person was the treasurer of the carer support group; again a person not employed by the practice. At the Penzance practice, the PCC was a community nurse employed by the Community Health Trust; and no one was identified to act in her absence. Only the Constantine practice had a named person responsible for acting in the absence of the identified PCC (practice receptionist) and this was a member of the nursing staff. The district nurse employed at the Gunnislake practice was the nominated PCC for this practice.

Table 1: PCC Roles & Responsibilities by Practice

	Constantine	Gunnislake	Mullion	Penzance
Length of time in role of PCC	20 months	2 years	2 years	2 years
Main responsibilities:				
Maintain register of carers	✓	✓	✓	x
Maintain system for identifying patients who are also carers	✓	✓	x	x
Maintain recall system for carers	✓	x	x	x
Ensure carer status in patient notes	✓	✓	x	x
Ensure information for carers available & accessible	✓	✓	✓	✓
Send out information to carers as required	✓	✓	✓	✓
Ensure newly identified carers have access to relevant information & support	✓	✓	✓	x
Provide support to carers	✓	✓	✓	✓
Provide regular statistical summaries on numbers on register & numbers provided with support*	Not requested	Not requested	x	x

***N.B. None of the PCCs had been asked for statistical summaries and so none had been provided. It was not clear whether such information could be provided if requested.**

Two of the PCCs (at Gunnislake and Mullion) felt the responsibility of being the PCC added *greatly to their workload* ‘to a great extent’; and two ‘to some extent’ (Constantine and Penzance). Three of the PCCs (all except the PCC based at Constantine) felt they would like to see an individual employed within the practice specifically to fulfil the role of carer support worker.

Since the original carer support worker left the practices following implementation of the carer support worker service, the PCCs who participated in this study felt that the support offered to carers was *provided at an optimal level* ‘to a great extent’ (Constantine), ‘to some extent’ (Mullion and Penzance), and ‘not at all’ (Gunnislake). Additional comments provided by the PCCs to the interviewer gave further insight into this issue:

“When co-ordinator was in place she worked three mornings a week, now only six hours a month allocated and patients think she is a replacement for the original co-ordinator. Bereaved relatives still come to the group so feels there is a danger of it becoming a bereavement group rather than a carers group. Training for the co-ordinator e.g. counselling. Men on the list, but none attend the meetings or outings. Meetings every six weeks”. (Constantine PCC)

“Bring co-ordinator back! Says there is no funding for another designated co-ordinator from the practice. No designated hours for the co-ordinator duties – just added to present workload. Organises BBQ, Meetings/Outings. Attendance approx.18” (Gunnislake PCC).

“Need to expand the role as there is a need. Bring back paid co-ordinator – possibly shared by several practices. Shares role with another carer and feedback to the Practice Manager. Shortfall could be that they are ‘amateurs’. Need for Counsellor”. (Mullion PCC)

“In her role as community nurse assistant visiting carers she identifies people who could do with the support of the carers group. She thinks there is a need for a carer support co-ordinator who could put more time into encouraging the less outgoing carers to identify their problems and come to the meetings”. (Penzance PCC)

Response Rate & Characteristics of Carers

A total of 12 female and 8 male carers participated in the study. Five female carers were interviewed from the Constantine practice; two male and three female carers from Gunnislake; three male and two female carers from Mullion; and two male and three female carers from the Penzance practice. Despite our endeavours to interview similar numbers of male and female carers from each practice, male carers from the Constantine practice did not wish to take part in the study. Thus we have more female than male carers in this study. Approximately half of the carers were in the age range 46-55 years; only one of the carers was younger. The median number of years that the carers had been registered as a carer in the practice was 7.5 years. A summary of the characteristics of the carers by practice is shown in Table 2.

Table 2: Characteristics of the Carers by Practice

	Constantine	Gunnislake	Mullion	Penzance	Total
Male	0	2	3	2	8
Female	5	3	2	3	12
Age Group					
36-45	0	1	0	0	1
46-55	3	1	3	2	9
56-65	0	0	2	0	2
66-75	1	1	0	2	4
76+	1	2	0	1	4
Median Years Registered as Carer*	8	5	5	8	7.5

***N.B. This may not be a true reflection as some carers found it difficult to estimate the length of time they had been carers**

Results from the Carers Interviewed at the Constantine Practice

Identifying and Contacting the PCC

All five carers knew who the PCC was at their practice. One of the carers had seen the PCC within the past 4-7 days, one within 8-14 days, one within one month of the interview, and two more than one month prior to interview. None of the carers had difficulty contacting the PCC.

Provision of Information and Support

The three carers who required information felt the PCC provided this information immediately. If the information required was not known by the PCC at the time, this was provided within one week. The carers also felt they were given an opportunity to share their feelings, that they were listened to, and that the manner of the PCC was kind, gentle and friendly.

Perception of the Role of PCC

All five carers believed that the PCC was a valuable member of the practice team. Two of the carers felt that the practice should employ a person specifically for the role of carer support co-ordinator; one did not, and a further two felt they did not know. The reasons given by those who felt the practice should employ such a person were as follows:

- “To support the carers, organise meetings and outings, which gives them an opportunity to meet other carers and give them something to look forward to”

- “Co-ordinator should support the carers with mental and physical support. Should take over from Social Services the assessment and deployment of help for the chronic sick in their homes”

Perception of How the Practice Could Improve the Services Offered to Carers

Three of the carers felt that the services could not be improved; one did not know how improvements could be made, and the fifth indicated:

- “More contact with the surgery. Would like to see the Surgery as a one stop centre (e.g. organise respite care) for services and help. At present help comes from many different agencies e.g. Wheelchairs from Plymouth. Could provide training for carers in for example, lifting”

Results from the Carers Interviewed at the Gunnislake Practice

Identifying and Contacting the PCC

All five carers knew who the PCC was at their practice. Two of the carers had seen the PCC within the past three days, and three more than one month prior to interview. Two of the carers stated they had difficulty contacting the PCC, and two did not. The reasons given for this were:

- “Sometimes the duties (District Nurse) means she is not always available”
- “Because she is a District Nurse she has other duties. Leaves messages”

Provision of Information and Support

The two carers who stated they required information felt the PCC provided this information immediately. Information not known by the PCC at the time was provided within one week. The carers also felt they were given an opportunity to share their feelings, that they were listened to, and that the manner of the PCC was kind, gentle and friendly.

Perception of the Role of PCC

Four of the carers believed the PCC was a valuable member of the practice team. One did not answer this question on the basis that if help was required s/he would go to social services rather than the PCC. Two of the carers felt that the practice should employ a person specifically for the role of carer support co-ordinator; one did not, and a further two felt they did not know. The reasons given by those who felt the practice should employ such a person were as follows:

- “It is too much work for someone who has already got a full time job”

- “Advice and legal position regarding care in the home. Need for information on various aspects e.g. nutrition. One stop source of help and information”
- “Could give more time to look after carers’ needs, e.g. help with filling out forms”

Perception of How the Practice Could Improve the Services Offered to Carers

One of the carers did not know how services could be improved; four made the following comments:

- Was in contact with previous co-ordinator but now only deals with PCC as district Nurse. Would like to go on outings and meetings but cannot leave her husband as he becomes upset.
- Went to the BBQ. Co-ordinator put their name forward for a free holiday with the Lions. Feels that they could do more to support their situation, as they are young and have a family that makes their needs different.
- Doesn’t have contact with co-ordinator. Deals direct with Carewatch for support.
- The previous co-ordinator had more hours so could spend more time supporting the carers.

Results from the Carers Interviewed at the Mullion Practice

Identifying and Contacting the PCC

The five carers knew who the PCC was at their practice. One of the carers had seen the PCC within the past three days, one within the past 4-7 days, one within 8-14 days prior to interview, and two within one month prior to interview. One of the carers stated they had difficulty contacting the PCC, but no reason was provided.

Provision of Information and Support

All five carers stated they required information and that the PCC provided this information immediately. Four stated that information not known at the time by the PCC was provided within one week. The carers felt they were given an opportunity to share their feelings, that they were listened to, and that the manner of the PCC was kind, gentle and friendly.

Perception of the Role of PCC

All five carers believed the PCC was a valuable member of the practice team. Four of the carers felt that the practice should employ a person specifically for the role of carer support co-ordinator; and one did not. The reasons given by those who felt the practice should employ such a person were as follows:

- “Carers need a co-ordinator to provide support. Meetings provide an outlet for carers to talk about their circumstances otherwise they ‘bottle it up and keep it’. They need someone to talk to”
- “Provides a bridge between carer and patient. Provides point of contact to share problems and know what is available in terms of support and financial assistance”
- “To provide information and share experiences. Empathy”

Perception of How the Practice Could Improve the Services Offered to Carers

Three of the carers did not feel that current services could be improved, and one commented: “Meet once a month.....The best system so far.....Pro-active”. Two felt improvements could be made with regard financial advice:

- “Liase with Benefits Agency regarding benefits available”
- “Supporting the carers - happy with the services. Advise what financial help available”

Results from the Carers Interviewed at the Penzance Practice

Identifying and Contacting the PCC

Two of the carers knew who the PCC was at their practice, and three did not. The four who had been in contact with the PCC had seen the PCC more than one month prior to interview. Two of the carers stated they had difficulty contacting the PCC because they did not know whom to contact.

Provision of Information and Support

One carer stated s/he required information and that the PCC provided this information immediately. In addition, information not known at the time by the PCC was provided within one week. The one carer who felt able to answer issues around the PCC felt s/he was given an opportunity to share feelings, that s/he was listened to, and that the manner of the PCC was kind, gentle and friendly.

Perception of the Role of PCC

Three carers believed the PCC was a valuable member of the practice team, and two could not answer this question. Four of the carers felt that the practice should employ a person specifically for the role of carer support co-ordinator; and one did not. The reasons given by those who felt the practice should employ such a person were as follows:

- “It would be very useful for other carers who have greater need”

- “The previous co-ordinator was very helpful and was someone to talk to; she would listen and would also help with benefits”
- The carer’s wife died in March but when she was alive he would have liked to have had someone advise him about financial and other support which would have been available to him.
- The first co-ordinator wrote letters to the Council, Social Services etc. on their behalf. Applied to a local charity for disabled aids e.g. table. If she had a problem the co-ordinator would be her first port of call.

Perception of How the Practice Could Improve the Services Offered to Carers

Three of the carers did not feel the services provided could be improved. The comment made by the carer who felt improvements could be made was “Bring back the paid co-ordinator role”.

Summary of Results from Carers’ Interviews

Identifying and Contacting the PCC

Three of the carers from one practice (Penzance) did not know who the PCC was at their practice. Approximately 50% of the carers had been in contact with the PCC within the month preceding this study: three within the past month, two within the past 8-14 days, 2 within the past 4-7 days, and three within the three days preceding the date of interview. In three cases at Gunnislake, however, it was not clear whether the carer saw the PCC in her role as PCC or district nurse. Nine of the carers had been in contact with the PCC more than one month prior to interview. Eleven stated that they did not have difficulty contacting the PCC, but five did (25%). Four of the latter gave reasons for the difficulty: two stated the PCC had other responsibilities and was not, therefore, always available; and two did not know who to contact.

Provision of Information and Support

Those who required information felt this was provided immediately; and that information not known by the PCC was provided within one week. Those who sought help felt they were given an opportunity to share their feelings, that they were listened to, and that the manner of the PCC was kind, gentle and friendly.

Perception of the Role of the PCC

Seventeen stated they thought the PCC was a valuable member of the practice team. These were the carers who could identify the PCC and had used the service within the

month prior to interview. Twelve felt the practice should employ a person specifically for the role of carer support worker, four did not, and a further four could not answer this question.

Perception of How the Practice Could Improve the Services Offered to Carers

Nine of the carers felt happy with the services provided, and eight felt that improvements could be made. Suggestions were made for more time and support, more contact with the surgery, and more financial advice.

Some of the carers made additional comments; most of which were positive in nature and also described the carer's particular situation. One carer from Penzance, however, stated s/he had never been invited to a meeting for carers; and a second from Gunnislake stated s/he would go to Social Services rather than the PCC for assistance. In addition, another carer from Gunnislake who is young, caring for a young wife and two children felt that the meetings and social events were not suited to younger people.

Discussion

The results suggest that there has been mixed success with regard to the lasting impact of the carer support worker service first implemented within the practices. The roles of the carer support worker were clearly identified (see p.5) and yet not all of these functions are being maintained by the PCCs within the practices; provision of information to the carers was the only task undertaken at all four practices. The systems necessary for maintaining a register of carers, identifying patients who are also carers and flagging such information in the patients' notes, and maintaining a recall system for patients are only all in place in one practice. The reasons for this may be linked to the person at each practice undertaking the role of PCC. In two of the practices, the identified PCC was employed by the practice, and in both cases, more of the identified tasks of the carer support worker were being performed. In the other two practices, one PCC was a volunteer, and the second a community nurse not employed by the practice. In these cases, some of the questions relating to maintenance of registers etc. were not relevant. The additional responsibility associated with being the identified PCC was articulated strongly by the PCCs, three of whom felt the practices should employ an individual specifically for the role. Two

of the four PCCs also felt that they did not have the skills required for dealing with carers (e.g. counselling skills) as they were not professionals. This issue was also emphasised by one of the carers interviewed who felt s/he could not share her feelings with the PCC, as this person was a carer herself. This highlights the importance of ensuring a professional role to the position and how the credibility of a group leader can be undermined if there is a perceived lack of professional expertise. In the case where the PCC was also the practice receptionist, none of the men on the carers' register attended the carers' meetings. There may be several reasons for this but the influencing factor of the usual role within the practice of this particular PCC should be considered.

The carers interviewed were very appreciative of the services offered, and felt supported by their PCC. However, 12 of the 20 carers interviewed felt that the practice should employ a person specifically for the role of carer support worker. This is consistent with the views expressed by the PCCs. Furthermore, three of the carers from one practice did not know who the identified PCC was at their practice; and five carers had difficulty contacting the PCC. What was common to all the carers interviewed was that they knew who the original carer support worker was; in addition, the original carer support worker made a point of contacting all the carers. With the present system the PCCs do not have the time to follow up individual carers. In the two practices where the PCCs were also nurses, the carers did not always differentiate between the two roles. These findings are reiterated by the views of one of the practice PCCs (employed by the practice) who felt the service she provided was much reduced from when the original carer support worker was in post.

Conclusions and Recommendations

The design of the study limits the findings in as much as no information was collected prior to the implementation of the carer support worker service. However, clear guidance was given with regard to the roles of the carer support worker including the need to maintain accurate registers. While the carers interviewed viewed the carer support service offered to them in a positive manner, it is clear that both the carers and the PCCs perceived a need to have a person employed by the practices specifically for the role of carer support worker. There is an additional burden in terms of the workload associated with the role of carer support worker which may prevent the

work being undertaken in a manner most suited to meeting the needs of the carers. It is of concern that male carers on the register of two of the practices did not attend the carer support meetings organised by the PCCs. Further research needs to be undertaken to establish whether they do not attend the meetings because they see no need, or whether they feel inhibited in some way.

This study was also limited with regard to the number of carers interviewed. While an attempt was made to include similar numbers of males and females, we could not extend this to include representation of a variety of age groups. There was only one carer aged less than 46 years and none aged less than 36 years. Further work is required to evaluate how carers from different age groups perceive the carer support service as well as males and females within different age groups.

The variation between practices with regard to the extent to which the identified tasks associated with the role of the carer support worker were undertaken, leads to some suggestions for a way forward:

- Agree the key elements of the role of the carer support worker and determine what should be provided on a routine basis by the identified PCC.
- Determine an appropriate monitoring procedure to identify which elements of the role are effective and which are ineffective.
- If not already in place, ensure the working practice of the individuals nominated to take on the role of the carer support worker is reviewed regularly at a practice level and that support is provided as appropriate.
- Consider establishing a support system for identified PCCs to reinforce the importance of the role, and to ensure comparability in practice.
- Consider employing an individual within each practice, or shared between several practices, dedicated specifically to the role of carer support worker.

APPENDIX