Swedish experiences of a negotiated approach to carer assessment: the Carers Outcome Agreement Tool

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Abstract Given that the majority of frail older people living at home are cared for by family members, ensuring appropriate and sensitive support services for family carers is a major policy priority globally. Such assessment of the needs and situation of individual carers is a crucial first step towards ensuring that they receive flexible, quality support services. However, existing assessment practice is still inadequate in many countries. This paper describes a negotiated approach to carer assessment, the Carers Outcome Agreement Tool (COAT) and briefly considers its development with carers and practitioners in an Anglo-Swedish development project (2003–2005) and subsequent implementation within five municipalities in Sweden (2006–2008). A participatory research design was adopted in both projects building on the ÄldreVäst Sjuhärad model, which is a user-focused approach to research and development. This paper provides a short summary of the COAT development before presenting the qualitative findings from the Swedish implementation project (2006–2008), which emerged from focus group interviews with COAT practitioners and telephone follow-up interviews with carers who had a first and second COAT assessment. The findings clearly highlight the value of COAT in enabling partnerships to be developed between carers and practitioners, which recognise the expertise of both parties. They also challenge providers to invest sufficient time and 'ear-marked' resources for family care support so that COAT becomes an integral part of a

comprehensive long-term carer strategy, which feeds directly into local developments in service delivery and organisation.

Key words assessment; family carers; negotiation; partnerships

Introduction

The majority of care for frail older people living at home is provided by family members, and consequently ensuring appropriate and sensitive support services for family carers is a major international policy priority (Nies, 2004). Despite an extensive empirical literature and numerous policy initiatives, there remains a lack of evidence about the effectiveness of current support services for carers (Mestheneos and Triantafillou, 2005). Furthermore, carers often have concerns about the quality of care they or their relative receive and many reject help as a result (Brodaty, *et al.*, 2005). At the same time, despite the recent rhetoric about the need for practitioners to work in partnership with family carers, services still tend to be allocated to carers based upon pre-determined eligibility criteria (Nolan, *et al.*, 2003) with the practitioner acting as a 'gatekeeper' to such services. A recent international symposium exploring family caregiver assessment in Canada, Australia, UK, Sweden and Australia (Feinberg, 2007) concluded similarly to the Audit Commission (2004) UK wide review of carer assessment that appropriate and sensitive assessment is paramount but that despite progress existing practice remains inadequate. In the UK for instance, there is a legislation providing carers with rights to an individual assessment, but such assessment is not widely promoted and carers themselves are often unaware of their rights in this regard (Audit Commission, 2004; Nolan, *et al.*, 2007).

In Sweden, there has recently been increasing recognition of the central role that family members play in the care of older relatives. The late 1990s onwards witnessed a succession of state grants to stimulate support for carers, with a focus on the development of flexible and sustainable services based on partnerships between formal care providers, the voluntary sector and carers themselves. In January 2008, a National Family Care Competence centre was formally established with the aim of enabling long-term knowledge development in family care of older people, including how support can best be given to family carers.

Furthermore, there are likely imminent changes to the current Social Services Act giving municipalities a formal responsibility to provide carers with appropriate support services; this is likely to necessitate individual carer assessments. However, currently, few municipalities conduct systematic assessments, and those that do tend to operate a procedural model (Smale, *et al.*, 1993) whereby services are allocated largely on the basis of pre-determined criteria. This has led to a 'one-size fits all' approach with little scope for innovation or flexibility, with support focussing primarily on practical help and reducing carer burden rather than developing more creative solutions aimed at increasing the satisfactions of caring and/or finding ways of enhancing the caring relationship (Hanson, 2007).

It was the desire to develop a more flexible and negotiated approach to carer assessment that led to the development of the Carers Outcome Agreement Tool (COAT) (Hanson, *et al.*, 2006). This article begins by outlining the theoretical underpinnings of COAT and how it was developed with carer and practitioner involvements (2003–2005) before moving on to highlight the initial findings from an ongoing 3-year research and development project in which COAT is being imple-

mented in five municipalities across Sweden (2006–2008). The article concludes with some thoughts on future developments in this area.

Background to COAT

COAT builds on over 15 years of work in carer assessment (Nolan, *et al.*, 1990, 1994, 1996, 2003) and is underpinned by the 'Carers as Experts' model (Nolan, *et al.*, 1996) that views carers and practitioners as 'co-experts'; each with differing but complementary forms of knowledge and expertise that, when shared, provide a more complete understanding of the caring situation. The main aim of COAT is to enable carers and practitioners to 'exchange' their knowledge and insights and negotiate sensitive and appropriate support (Hanson, *et al.*, 2006).

COAT is based on outcomes that are carer focused and was informed by the work of Nicholas (2001, 2003), who argued that services not only must focus on outcomes that are relevant to carers themselves but also give due consideration to the views of practitioners and managers (Nicholas, 2003). Nicholas identified four domains, which have been used to help inform the development of COAT. These are:

- A good quality of life for the cared-for person.
- A good quality of life for the carer.
- Recognition and support in the caring role.
- Service process outcomes (e.g. are services delivered 'on time' and are they of high quality).

An initial version of COAT was generated drawing on items from existing carer assessment tools (Nolan, *et al.*, 1996, 1998) and comprised five main elements, four sets of questionnaires and an action/evaluation plan for each of the questionnaires. The four questionnaires addressed the following domains:

- Helping you to care, which considered the type of help, information and skills that carers might need.
- Making life better for you, which explored support that might improve the carer's quality of life.
- Making life better for your relative, which explored what might improve the quality of life of the cared-for person.
- Getting good quality help, which considered what carers wanted from a quality service.

Completion of the questionnaires is intended to enable carers and practitioners to identify key areas for support and negotiate the goals of specific services, hence COAT. Once the initial version of COAT had been constructed, it was subjected to further development and refinement using the ÄldreVäst Sjuhärad model (ÄVS).

Developing COAT

The ÄVS model is a user-focused approach to research and development adopted by ÄldreVäst Sjuhärad Research centre based at the University College of Borås, West Sweden which is a centre of excellence for research, development and education in the care of older people. ÄVS has a diverse range of stakeholders, including older

people and their families as well as health and social care providers, representatives of voluntary and pensionist organisations, politicians and researchers. A key aim of the centre is to bridge the gap between theory and practice by generating new knowledge that is presented in a way that is widely understood as possible (Magnusson, *et al.*, 2001).

In keeping with the ÄVS model, COAT was refined and tested with the active involvement of carers and practitioners in a collaborative project between ÄVS and the University of Sheffield School of Nursing (SoN), involving extensive consultation and field testing of the COAT model [see Hanson, *et al.* (2006) for more details]. Overall COAT worked well in promoting a personal and detailed discussion about individual caring situations, which enabled carers to reflect on their situation and raise important new questions. Interestingly, even though some assessors already knew the participating carers, they also gained new insights into the caring situation. As a result of the user consultation and a trial implementation of COAT, further changes were made to enhance its usability and make it feasible for use in routine practice. Such changes included the grouping together of similar questions, the addition of a 'not applicable' column and space for further comment (Hanson, *et al.*, 2006).

Implementing COAT within everyday practice

Following the initial conceptual and development phases, funding for a further 3-year research and development project was secured (2006–2008) from participating municipalities, their county administrative boards and ÄVS research centre, to introduce, implement and evaluate COAT within everyday practice in five municipalities across Sweden (Borås, Härnösand, Jönköping, Limhamn-Bunkeflo and Varberg). As with the initial project, a participatory research design has been adopted in which carers and practitioners were actively involved in the research and development process. Ethical approval for the project was gained from the ethical review committee at the Department of Medicine at the University of Gothenburg.

At the start of the project workshops about the value and philosophy of partnership working, and the exchange model of carer assessment including 'carers as co-experts' that underpin COAT were held for practitioners, representatives from voluntary and pensionist organisations and service providers across the participating municipalities. In addition, regular supervision sessions have been held during the project, and network meetings were organised every 6 months which act as a forum for all key stakeholders in the project to share their knowledge and experiences, and agree on the further development and refinement of COAT based on the evaluation results.

A range of qualitative and quantitative research methods are being employed to evaluate the impact of COAT in the participating municipalities:

- Questionnaires to family carers at the outset of the project about the quality of existing carer support services and thereafter every year to explore the perceived impact of COAT.
- Focus group interviews with practitioners at the beginning of the project and thereafter approximately every 12 months.
- Telephone interviews with family carers after a full COAT assessment and approximately every 12 months thereafter.
- Analyses of the completed COAT instruments and action plans.

Table 1 Characteristics of participating municipalities

Borås is a city in the West of Sweden to the southeast of Gothenburg with a population of approximately 100,000 inhabitants. Borås municipality consists of 11 districts of which seven are involved in the project and are implementing COAT. A range of respite care services are offered, including carer 'drop-in cafés' and an ICT-based support service.
Jönköping is a city with 123,000 inhabitants on the south coast line of Lake Vatten in Småland, in the mid-south of Sweden. The municipality offers different forms of respite care and financial benefits for carers, along with family carer support groups.
Härnösand is a semi-rural town with 25,000 inhabitants in the northeast of Sweden. It has a well-established family care centre which is run in close co-operation with voluntary and pensionist organisations, and includes education sessions and support groups for carers.
Varberg is a coastal spa town on the west coast with 27,000 inhabitants and has a well-established and extensive range of flexible and individualised family care support services.
Limhamn-Bunkeflo is a district in Malmö with 33,000 inhabitants and offers its family care support services, include respite care and family carer groups.

Here, we concentrate on the views and experiences of carers and practitioners about the impact of working with COAT during the first year, especially the extent to which it promoted partnerships between family and formal carers, which recognise the expertise of both parties.

Five municipalities from across Sweden constitute the COAT implementation project, and these are summarised in Table 1.

Focus group interviews were conducted in each of the five participating municipalities with all the stakeholders directly involved in the local implementation of COAT at the outset of the project. In total, 35 people took part. These explored participants' expectations of the project, their views about family care support, including their initial views about COAT, and their specific plans for implementing COAT locally. Additional focus groups were carried out approximately 12–18 months later to explore their experiences of working with COAT, its perceived impact on participating family carers, their own practice and the municipality's organisation and planning of family care support services including perceived benefits and challenges. In total, 38 people took part (Table 2).

Telephone interviews were conducted with a sample of consenting family carers approximately 1 week after they had taken part in a COAT assessment. A purposive sampling technique was chosen to ensure that there was a heterogeneous group of

Table 2 Participants in the practitioner focus group interviews

	Focus group interview	
	Initial	Follow-up
Amount of participants	35	38
Participants from voluntary organisations	1	3
Need assessors, social workers	4	1
District nurses, dementia nurses	3	3
Care workers/assistant nurses/family care advisers	19	21
Family care officer, elder care officer, elder educationalist	3	5
Mental health and dementia care specialist adviser	1	1
Managers	2	2
Planning and development officers	2	2

Table 3 COAT carer participants in the telephone follow-up interviews

	Interview	
	One	Two
Amount of carers	54	38
Gender		
Male	18	15
Female	36	23
Age	47–91	55–92
Time as carer	1–25	1–31
Relationship		
Spousal/partner	44	34
Children	7	4
Other	2	
The cared-for person's illness		
Physical	28	23
Dementia	8	16
Physical and dementia	9	
Psychological	10	

carers with regards to age, gender, relationship to their relative, length of time as a carer and the main illness of the cared-for person. In total, 54 carers took part in individual 'follow-up' interviews during 2006, and 38 carers took place in a further 'follow-up' interview approximately 1 year later (Table 3).

The schedule for the initial interviews focussed on carers' experiences of COAT, and their reflections on COAT compared with prior assessments, followed by more specific questions about the questionnaires and action plans. At the second follow-up telephone interview, a series of open-ended questions focused on their recent experience of the COAT assessment compared with the first assessment, their views about the support they initially agreed and whether it had been provided, an exploration of any newly identified needs and planned actions taken, their views of the 'follow-up' visit in between the full COAT assessments and their overall views about the way of working with COAT, including suggestions for improvements.

With the participants' permission, the individual and group interviews were tape-recorded and transcribed verbatim. The interview data were content analysed to identify key themes, and illustrative quotes were included to ensure that the participants' experiences and views were given priority. Constant comparative technique was used to identify positive and negative aspects of COAT among family carers and professionals (Glaser and Strauss, 1967). The main findings from the focus groups were summarised for each municipality, and for the carer interviews, each individual interview was initially analysed and an individual summary provided, followed by an overall summary of the key findings of the carer interviews for each municipality. Commonalities and differences across the five participating municipalities for both the focus group and individual interviews have been identified.

Findings

Although each of the municipalities had used differing groups of staff to conduct their carer assessments, as per local practice, participants across the municipalities all

saw COAT as a systematic approach that assisted their respective municipality in their work with family care support in a variety of ways, including:

- Enabling the municipality to base future decisions and priorities for family care support on carer's own views.
- To better understand why existing support was not always accepted and to create more individualised and flexible forms of support.
- Providing an evaluation system for family care support.
- To work proactively rather than reactively with family carers.
- To increase awareness and recognition of the situation of family carers in the municipality as a whole.

Participating in a collaborative project involving several municipalities also enabled the sharing of experiences, allowing municipalities to learn from each other and to find solutions for common problems, including ways of improving family care support services.

At the same time, a common concern was the challenge of recruiting carers and reaching those not already known by care services. Prior to the implementation, practitioners also voiced concerns about raising carers' expectations that they might be unable to meet, and of the time they perceived it would take to complete COAT.

At the follow-up interviews, there was an overwhelming consensus that the most positive and rewarding aspect of COAT was the in-depth discussion it facilitated with the carer, with several assessors commenting that this enabled them to raise delicate issues that might have been overlooked in the past:

> I felt that it was good with these four different main areas, because you really do get close to the person who you're interviewing. I don't think I'd ever have been able to draw out these things otherwise. By using these questions it gets to be a really good discussion and you get out a lot. They act as triggers.

As a result, assessors were able to gain a much more detailed and comprehensive understanding of the carer's specific situation, and consequently to develop a closer relationship. Several assessors noted that carers felt their views were listened to and they openly expressed their gratitude for the assessors spending time with them. However, this also proved very affirming for the assessors themselves:

> You get a better understanding for how things are for them [carers] and you come closer to them in a completely different way than before. You understand that they have it really hard at the same time you see that you can give them tips and advice along the way. Someone said to me that we come up with things together and that gives them a mental boost too. It isn't just practical advice and tips but also to think in different ways. They often have ideas within themselves- it's just that you can bring it to their awareness. It's really good. It's one of the most interesting things I've done so far is go out and do these interviews.

Essentially COAT enabled the implementation of a model that placed the family carer at the centre. In addition, however, it raised the profile of carers amongst key decision makers, other staff working with older people and their carers and to the wider population of the municipality. Such experiences varied with participants in Jönköping and in Limhamn-Bunkeflo in particular believing that important part of their work within the COAT project involved explaining COAT to other practitioners, care providers and representatives from voluntary and pensionist organisations.

Jönköping was unique in that the family care advisors there had sufficient specific time dedicated to working with COAT, whereas in several other areas practitioners often had to juggle the COAT project with their existing workload. Those in Jönköping, therefore, had more extensive experience of the benefits of COAT. The overriding consensus from participants in Jönköping was that carers generally asked for relatively very little help in the form of services. Rather, they valued the discussion and the information that was given during the interview. In this way, they regarded the session as therapeutic, giving the carer a greater sense of security. Moreover, an established relationship between a family and staff gave the carer time to gradually reflect on the benefits of accepting help:

> I feel that the greatest advantage with COAT is that you meet in an arena that's not under the jurisdiction of the authorities. For help to be accepted from outside it must be offered in a way that the family can accept it and have the opportunity to gradually bring it into the family.

However, reaching this point did require an investment of time and effort from the practitioners that those in other areas struggled to match:

> But it is a bit difficult, or rather it is difficult to take that step in your work you know, that you'll disappear for those two hours after lunch or two and a half or three. It's that bit really. Because there's so much else that's got to be done too, that there are not enough staff.

The difficulties associated with finding and recruiting new family carers were also highlighted in the follow-up group interviews. For example, in Limhamn-Bunkeflo practitioners had developed a range of strategies including individual contact with social care officers, district nurses alerting local medical centres, local family carer associations and the church, together with the use of the local paper. Carers from immigrant populations proved particularly difficult to identify.

Another challenge was to identify carers at a sufficiently early stage so that effective support could be provided when it was needed most. The help of the primary care team was very important here:

> They're so burned out the relatives so that when you do the COAT interview it often comes up that they need short term respite care but then after two months that doesn't work either and it's nursing home so then you've already had to finish COAT quite early, in half a year it's already finished. We must come in early. And earlier is in primary health care. They must inform carers that they can contact the municipality and that there are different types of family care support available.

Another common issue was the COAT assessor not having formal authority to be able to grant the help and support that had been agreed upon. Where this authority existed it made the COAT far more effective:

> I've found that this has been much easier. Because during the COAT discussion I've captured so much information so that when we do the action plan I can already give an answer as to the benefit. It's as easy as anything.

In some areas, such as Borås and Limhamn-Bunkeflo, COAT raised the need for more flexible and innovative forms of respite care; that met the carers' needs rather than those of the municipality:

> Then the municipality must work with respite care places, short term care places. There's not enough. We don't listen to the individual rather we say that now there is a vacant place. But it's not when they want it rather the other way round. Probably they want it for three days or so but from the municipality we say but you can have it for a week… because it fits in with our planning.

Overall, the majority of the focus group participants considered that the COAT interview was valuable for both the carer and the practitioner as individuals, and also for the municipality as a whole, as it led to increased recognition of the situation of family carers and enabled a more explicit vision for how to work with family carers to emerge. Key challenges centred on constraints of time to implement COAT and the difficulties of identifying and accessing carers, particularly for hard to reach groups, as early as possible.

Initial family carer telephone interviews

Data from the initial interviews indicated that carers were overwhelmingly positive about the COAT interview, as it enabled them to play an active role and then decide together with the assessor what support should be provided:

> It was that we had such a good discussion and that we could talk about this—this was what I liked the best about it all. It felt like what I said was written down and it went home and she focused on that.

During the interview the assessor was also able to clarify several issues, whilst still empowering the carer:

> I felt that she was a very good support for me because if I was unsure she explained it in an easy way-that this is the thinking behind this… It wasn't that she said the answer herself but she guided me. And to do this in consultation with someone who I felt was so good was no problem.

When asked what they specifically valued about COAT, many carers felt that it formally recognised their role and situation and made them visible:

> It was good, it felt secure, that there's someone who cares about those who are carers because it's tough I can tell you. No, but it was good that someone saw me. That's the best. It's quite clear that I felt I was seen.

Likewise, many participant carers explained that COAT helped to increase their understanding of their own caring situation, and how to get support:

> It became clearer for me what I need help with and how I can apply for help and who to get in touch with to get help. I thought it was great that everything that I feel is hard going became so obvious when we did the action plan together.
> I'm not especially good at formulating things but I felt that it [COAT] raised quite a lot of thoughts when I saw the questions and you think of things and perhaps you've thought of that before but when you see it like this it's more,,, yes you really get to think about it. We arrived at what's important for me and what's important for Dad. And it's 'what are the goals of the help and support and how do I know that it's helped. I hadn't thought so much about it before actually.

Furthermore, going through the COAT items and action plans together with an assessor enabled a number of participant carers to gain individualised information about their needs:

> I felt it was good to read first and talk about how I felt and about my situation in relation to the questions. So I feel the questions were put together well. We sat there together and went through everything so that I got some good information just about these things when we sat there and filled it in.
> I feel that, you know when you're old and you're in the situation that I'm in that my wife's sick. Then, you're in a situation that you don't know who to turn to. You're a bit unsure yourself and it's quite hard when you're much older. I think it's definitely an advantage that you get… there was quite a lot of information I got and I think it was good.

At the same time, COAT helped participant carers to feel more secure with regards to their own caring situation:

> I can feel calm you know. I know that I can call someone when I need to if my wife gets more poorly or such a situation and you know it's a security for me that's how I feel, that I can take a deep breath out. That there's someone who can support me in that situation.

A number of participant carers also recognised that whilst COAT helped them personally, it was also a more systematic way of working with family care support within their respective municipality as a whole:

> It's good because they can't decide things a week at a time, they must take a long term view and then you need to have some main points to go from which are put together, I understand that. It was good, the more you know, the better it'll be.

Despite, the overall positive experiences expressed by the majority of the carers, some participants early in the caring trajectory did not see themselves as carers and felt that many items were irrelevant. Nevertheless, they thought COAT helped to prepare them for what to expect in the future:

> Mm, well a lot of the questions didn't really apply to me –you see my wife is still able to do a lot of things for herself. But I suppose on the other hand, it helps me to know what to expect- she has a dementia and it will get worse.

Despite the benefits, a number of carers felt that the instrument was rather long, with some overlap between questions. However, there was a lack of consensus about which items were redundant. Several carers also found it difficult to decide on the alternative answers, but this often became clearer during the discussion with the assessor. Several participants acknowledged that COAT took time to complete, but they also felt it was important to be able to discuss their situation and plan for the future in peace and quiet.

Overall, the initial telephone interviews indicated that COAT facilitated an in-depth discussion between the assessor and carer about the carer's specific needs, and helped them to agree on the goals and type of help and support best suited to individual carers. The experience was valued by the carer because it led to an increased recognition of their situation; they gained appropriate information and it helped them to feel secure. At the same time, they could see that COAT enabled the municipality to work more systematically with family care support. Areas that attracted less favourable comment were more practical in nature and centred on the extensiveness and format of the questionnaire 'per se' rather than the way of working. Such issues were often

resolved during the course of their discussion with the assessor, and can in part be seen as both assessor and carer coming to terms with a differing way of working.

Follow-up family carer interviews

When carers were asked to compare their experiences of the initial and second full COAT interviews, most of the benefits remained and a number of carers commented that it was easier the second time around as they knew what to expect, understood the purpose of the exchange, and were familiar with the questions.

> I felt that quite a lot had happened and it was much easier this time you know. I'd thought about these questions and items and problems and so it had fastened in my head in a way and it was easier to think in the same track again. And I'd made a mental note of certain things and tried to solve problems myself or at any rate tried to reach a better situation.

A number of carers also admitted that they felt they were able to speak more openly the second time and had more insight into their caring situation compared with the initial interview:

> I think I was possibly a bit more open this time. I don't know, I think I said more what I thought. The first time I thought that it wasn't anything, being a carer. You do it anyway. I mean I'm married to my husband. And then you help each other out. It was more perhaps that I'd accepted more now that I'm regarded as a carer.
> .. I had more insight into what it was all about because I've been experiencing these things. Yes, a lot is what you've already experienced but you perhaps see it in another way after you've gone through it like this.

The majority of carers across the participant municipalities valued having a discussion with an assessor even if it was a different person who came the second time. They considered that the staff played an important role as they felt they were listened to and they were able to share their thoughts with them:

> The staff are always so rewarding and the best thing with the whole project in my point of view is the staff. I'm absolutely clear about what I need in my situation. It's a sounding board and someone whose experienced and understands the whole situation and when there are crises.

As a result, many carers considered that the second full COAT interview was a natural progression from the initial COAT session in which they followed up the support that had been agreed. Several mentioned the importance of having a contact person, who they could really trust and confide in and to whom they could turn should the need arise:

> The positive thing with this is that I feel at the same time that it's a support that I have this contact. If I want an answer to something I knew who to get in touch with.

However, there was a notable exception, and one carer openly admitted that she had not found the second interview as positive as the first time around because it had not been the same person who came and visited her. She felt that there was not the same 'personal bonding' between them as there had been with the first COAT assessor.

Several carers had difficulty recalling the follow-up sessions that were scheduled to take place in-between the two in-depth COAT interviews or they openly stated that they had not any specific follow-up contact with the COAT assessor. However, others

considered that it had worked out well with the follow-up contact they had either via the telephone or as a home visit, because they felt that the assessors were pleasant and experienced. Very few carers had made direct contact with the COAT assessors themselves, but they felt that they were available should the need arise:

> The positive thing about this is that at the same time I feel that it's a support that I have this contact. If I want to know about something I know who to get in touch with.

The majority of carers felt that they had received the help and support they had agreed on and were satisfied for the most part with the quality of the support they'd received. The most important and commonly requested type of help and support mentioned by carers was some form of respite care:

> I think the best thing they came up with is short-term care. You can be busy for a fortnight and then you can relax for a fortnight. At first I couldn't relax. I was sad and couldn't sleep at night but now I've reached the stage where I feel I can relax when I leave her.
> My husband stays every four weeks in a short-term care setting, that's what we have. It works very well. In the beginning, it was very difficult and I felt guilty, but now it feels better. It was everyone's choice but his about respite care. So the staff talked with him and he promised he'd give it a try. And it's worked out well. I can honestly say it's like a weight has been lifted from my shoulders.

However, there were still a minority of carers across the municipalities who were dissatisfied with the inflexibility of home care services or respite care services, and this led to several of them refusing the service:

> Home care were going to come here and wash father. On the first day they were due; we waited and waited and waited. At eleven o'clock I showered him. Then we came down and ate. And then in the afternoon, at two o'clock, the doorbell rings and there's a girl at the door whose going to shower my father. 'But do you do that when it's so late'? I asked. You don't mean that father's got to get dressed first and then take his clothes off to have a shower and then get dressed again, just before he's ready to take his clothes off again? (ready for bed in the afternoon). So, it didn't work out well at all. So then we didn't bother with the help.

Several carers who were granted respite care for their relative, were unable to take up the support offered as their relative refused, or the carer concerned felt unable to leave their relative due to fears about their well-being in their absence. Another issue raised by individual carers included home care staff that were stressed due to their work schedule, which in turn negatively affected the carer:

> They showered him and then it was like 'schumm'—[noise which describes how quickly they did everything] They were due to do this and they were a bit late anyhow. So I said that I'll sort out everything in the bathroom and the bed and things there, so they left as fast as they could.

Approximately half of the participant carers explained that they had not planned any new help and support this time round mainly because their needs had been met at the time of the initial COAT. Conversely, a number of carers admitted that their needs for help and support remained unchanged and that they had not been fully met. The unmet needs identified included: being able to choose staff (specific home care workers); to have regular visits from the occupational therapist and physiotherapist; to have a specified diagnosis from the doctor; to have more regular contact with the dementia care nurse.

When asked to reflect over the overall approach to family carer support adopted within the COAT project, the majority of carers were overwhelmingly positive and identified several key issues, including:

- They felt that the municipality had a better understanding of what worked well, and what needed improving, based on carers' own views:

  I feel it's good, for those that can improve things because if we have some criticisms or other views then they can change it or improve it. Or, add to it or take it away. You must know how you're going to work, so you don't just go from your point of view. It's good to know what we think as we're the ones who have the problems.

- Having a personal contact in the municipality gave carers a sense of security with regards to their caring situation:

  I think it's great because I like her very much, XXX who comes. I feel we get on well together and I feel she's very understanding. It feels like she's my sounding board when it concerns this (caring situation).

- It was good to talk openly about their caring situation:

  It's very gratifying and rewarding, it's gratifying that she comes and it's a rewarding discussion, so I look forward to the next visit, I think it gives a lot.

- Carers have the opportunity to voice their opinions and say what they think about their individual caring situation and the municipality's family care support services:

  I think it's important, that you really have the chance to give your views and really say what you think about things that affect you.

- It helps carers to make informed decisions and plan for the future:

  These thoughts, or these discussions have led me to a certain extent to write down a plan about things and try to plan in different things, to make it easier with one thing and another, according to our discussions and its thanks to this project that I've started with this and it gives a lot more. It's given me more self-confidence when I notice that I've been able to fix this and that, so that's thanks to the project.

- Carers have a better awareness of the help and support that is available and who to turn to for help:

  I think it's very valuable, it's given me a great deal and I feel it's a good way to take care of people who find themselves in this situation. I don't feel at all uncertain about who to turn to if I should have a problem. And I've had very sensible answers. And it's so important as a relative that you're treated as I've been treated. And I've raised this with other too. I feel very satisfied with this.

Despite such obvious advantages, several few carers expressed concerns about whether there would be sufficient economic resources for wide-scale implementation of the model within everyday practice in their respective municipality.

A few carers also noted that they still found some of the questions difficult to answer, but no specific suggestions for improvement were put forward. Likewise, there were no direct suggestions for improving the way of working with COAT.

The follow-up interviews confirmed the importance of the personal contact with the COAT assessor and the value of the in-depth discussion about their caring situation, which was seen as therapeutic in itself. Whilst a number of carers had received help and support since the first COAT assessment and were satisfied with it, there were others that had rejected the services offered either because they lacked sufficient quality or flexibility or they were not deemed to be acceptable by the person they cared for.

Discussion

If we reflect upon the goal of COAT and its aim to promote an exchange of information and expertise between carers and assessors, it is apparent that considerable progress has been made. The voices of the participant carers were clearly heard and actively listened to and valued by the COAT assessors, with the questionnaires enabling a range of issues to be explored and potential solutions identified. Thus, COAT facilitated a genuine dialogue between the 'factual knowledge' of the assessor and the more 'situated' and 'personal' knowledge of the carer resulting in a fuller and more holistic understanding of the individual carer's situation. In this way, the expertise of both parties was shared and neither party was seen to be superior to the other (Nolan, *et al.*, 1996; Barnes, 1999; Magnusson, *et al.*, 2001).

COAT also enabled carers to reflect upon their situation in a considered way, this was greatly facilitated by the personal skills of the assessor and their ability to help the carer think through difficult issues. A trusting relationship was essential and was often the thing that carers valued most.

Whilst the great majority of carers were extremely satisfied with their relationship with the assessor, the notable exception was one carer who could not develop a therapeutic understanding with the assessor at the second discussion.

However, COAT was not only useful in facilitating discussion but also resulted in changes and improvements to services, whilst raising awareness of carers needs more generally. It is clear from both the focus group and interview findings that a number of carers recognised the need to have more regular and sustained breaks from caring, as this was the most commonly requested type of family care support. This finding is not surprising given that the majority of carer participants had been caring for a considerable period of time and carried out substantial caring activities on a regular basis.

The overwhelming impression from the qualitative data was that the COAT assessments are empowering at the level of the individual carer, and the COAT sessions were seen to be therapeutic in and of themselves, providing an invaluable form of emotional support for the carer. They enabled the carer to talk in-depth about their caring which not only led to new insights but often additional help and support making their everyday life easier. At the same time, COAT was a means for the assessor to form a helping relationship with the carer which gave the carer an increased sense of security and provided intrinsic job satisfaction for the assessor, affirming that their work was valued.

Nevertheless, there was also evidence to suggest that there were a number of carers across the participant municipalities for whom the COAT did not lead to specific change for the better in their everyday life. This was due to a number of reasons. Some were unable to take up the offered help because the respite care service was

unacceptable to the cared-for person. This issue is well documented within the caregiving literature (Brodaty, *et al.*, 2005) and points to the need for practitioners to work together with both the carer and cared-for person and build up a trusting relationship so that over time a suitable solution for both parties can be found (Nicholas, 2003).

There were also carers across several municipalities who rejected the respite care service they were offered because it lacked sufficient quality and/or flexibility. This is a common problem that has been highlighted within the empirical and policy literature and relates to a larger resource issue within the municipalities. Currently, there remains wide variation in the quality and range of family care services within municipalities across Sweden (Magnusson, *et al.*, 2005; National Board of Health & Welfare Sweden, 2007). There has been intensive and sustained lobbying from carer organisations for a change in the Social Services Act making it obligatory for all municipalities to provide help and support for carers.

The initial staff focus group findings indicated that a number of practitioners were concerned that COAT might raise expectations amongst carers that could not currently be met. Clearly, both the carer and staff interview data confirm the need for more flexible and individualised forms of respite care, as does the quantitative data not reported here. Bi-annual and/or annual progress reports for the COAT project have been produced for each participant municipality and in Borås and Jönköping municipalities, they have formed an integral part of their next action plans for elder care and family care support. However, sustained change at an organisational level takes longer than 2 years, and further implementation work with COAT is required to see the long-term benefits of this approach.

There are several additional unresolved issues that were highlighted within the staff focus group data that also relate to resource issues. In particular, within several municipalities staff expressed their discontent with the lack of sufficient dedicated time to work intensively with individual carers including in-depth interviews and follow-ups; recruitment work to find carers early and reach out to less well-known carer groups (working carers, carers from ethnic minority groups) and active cooperation with other health and social care professionals and representatives from voluntary organisations. The notable exception was Jönköping municipality where the family care advisors were allocated sufficient dedicated time to work with COAT as an integral part of their family care support work. This highlights the importance of key decision makers in elder care within the municipality actively endorsing a partnership approach by providing appropriate resources and ongoing support. It is widely recognised that good assessment may take additional time but that the extra effort is worth the effort in terms of benefits to carers and the people they support (Guberman, 2005).

Conclusions

Supporting family carers is now a 'global issue' (Stoltz, *et al.*, 2007), but in the past any help provided has been 'given' to carers on a more or less 'take it or leave it basis', rather than being negotiated and agreed as a result of a shared understanding of the caring situation (Stoltz, *et al.*, 2004). This was due in large measure to the fact that assessment tools and models employed did not capture the nuances of family care, nor create the sense of 'togetherness' between carers and assessors that is needed for good relationships to develop (Stoltz, *et al.*, 2006). It is now widely recognised that the 'process' of assessment is a key element (Whitlach and Feinberg, 2007) and

that this should build on carers' strengths and resources as well as addressing their need for support (Nolan, *et al.*, 1998), and be based on a partnership built on trust, respect and good communication (Yeandle and Buckner, 2007). The use of COAT to-date suggests that it can facilitate the interdependent relationships that carers value but that this requires attentiveness and responsiveness by assessors (Schoot, *et al.*, 2005). These are demanding skills and require the investment of time and effort. This raises important political questions about genuinely investing in family carer support (Whitlach and Feinberg, 2007) that need to be addressed if the full potential of COAT is to be realised.

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