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Comparing UK and Dutch Alzheimer Cafes against the new Quality Control

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Summary

This article shows how two Alzheimer Cafés (ACs) in the UK largely meet the new Quality Control Criteria (QCC) for ACs, and how they compare with the 68 Dutch ACs that have recently been evaluated for the first time against the QCC. It explains some of the adaptations that have been made in the UK ACs to accommodate local conditions and needs, and makes some recommendations about further possible changes.

The 33 QCC for ACs are listed below in sections. The summary results of the Dutch and UK findings and future recommendations are provided under each section for easy comparison.

Background: the Origins of the Alzheimer Café concept

The Alzheimer Café (AC) concept was the idea of Dr. Bère Miesen in the Netherlands, in 1997. It was his solution to wanting to offer a more concrete kind of emotional support to persons with dementia and their families; to go beyond receiving a diagnosis, being given information about the nearest Alzheimer Society group and a contact for a social worker and psychologist.

He envisaged monthly group gatherings which would serve as a kind of 'low threshold' therapeutic group environment. Here, the dementia process- with all its visible and hidden difficulties could be openly discussed giving voice, particularly to the non-medical questions and concerns that are not normally discussed in other settings. These discussions were to be for all interested, but especially for persons with dementia, family members, partners, friends, in the presence of helping volunteers and health care professionals.

To hold the first AC, Miesen rented a lecture room at the University of Leiden. About two dozen persons attended. By the second meeting, there were about 75, by the third meeting the press was present, and publicity for this unusual endeavor helped the AC concept to start soaring. The AC moved to other premises, and, in the next year, seven-30 minute programmes were televised nationally, directly from the AC.

The 'Alzheimer Nederland' (AN), the equivalent of the UK national Alzheimer Society, adopted the AC concept and supported the development of a network which now includes 103 ACs. AN provides annual 2 day courses, to teach persons how to work with the themes and interviews at ACs, provide start-up funding for new ACS, and provide representatives and publicity for ACs. The AC idea has already spread to Belgium, the UK, Greece, Italy, Germany, America and Australia with other countries showing interest.

The AC concept is patented, but ACs can be set up by any group interested in adhering to the 'core concepts and philosophy' underpinning them. This has been written about on the website 'alzheimercafe.co.uk', and by Miesen and Jones (2005), and Thompson (2006). ACs are more than just 'pleasant social gatherings', and have many levels of education and support inherent in their design.

Development and evaluation of the Quality Control Criteria for ACs

The QCC were developed in 2005. Steering committees of 103 Dutch ACs were invited to self-evaluate against these criteria for the first time in 2006, as a way of finding out 'What existing cafes do well?' and 'What could be improved?' This evaluation was not initiated because of signals that the ACs were not doing well. To the contrary, AN wanted to use the evaluation of the new QCC to further stimulate good and best practice.

Sixty-eight evaluations were returned in time to be included in the analysis; others were too late, and some unable to do so since they had not yet finished their year programme. The QCC and results of the Dutch AC evaluation provided in this article have been extracted and translated from a report published by Alzheimer Nederland, with permission.

Given the great interest in ACs in the UK, it was decided to evaluate the first AC here (held in Farnborough, since 2000), and the one nearest it (serving East Berkshire, held in Bracknell since 2005), to see whether these ACs were in line with the original vision and current criteria, and to encourage other ACs nationally to self-evaluate and also, as a way of encouraging the further development of ACs.

Some differences between Alzheimer Cafés in the UK and the Netherlands

ACs have started in a number of locations in the UK, largely through the independent efforts of interested groups. Since ACs have not yet been formally adopted under a single national umbrella organization to develop their growth it is difficult to know the exact number. To our knowledge there seem to be about 20 currently, with an encouraging number in planning stages.

The [UK] Alzheimer's Society(AS) hosted a Teaching Day in 2002, to introduce the AC concept to several dozen interested people, however, at that time, the National AS did not take on leadership and development of ACs, as part of its own 'service-product' remit or vision. In 2006, the UK AS offered support for the development of ACs, as reflected in its job description for new Regional Managers. Currently, a further mini-conference about 'How to run an Alzheimer Café,' is being planned, so that the AC vision can be shared, developed and supported in a consistent way.

In reading this article, it is important to know that persons with dementia are diagnosed in the Netherlands, on average, two years earlier than those in the UK. In terms of the 'average figures' presented below, persons with dementia at Dutch ACs have better verbal abilities and participate in both interviews and discussions more than their counterparts in the UK. Access to anti-dementia drugs is not an issue in the Netherlands, as it currently is here. These differences are affirmed in Pharmafocus (2007).

The 2 UK ACS evaluated in this study

The two UK ACs evaluated in this article are those operating in Farnborough (Hampshire), and Bracknell (East Berkshire). The Farnborough AC has been operating continuously since Sept. 2000. The East Berkshire AC started in Oct. 2005. Originally it was intended to serve several of the local AS Branch groups in the area, but distance is proving to be a drawback for those living furthest. This AC is unusual in that it is the first AC to be set up at the initiative of a local Old Age Psychiatrist.

33 Quality Control Criteria for ACs

Both 'findings' and 'recommendations' are listed under Sections A to F, which also provide the 33 QCC by category.

A The vision and goals

Quality Control Criteria for an AC (2005)	Survey Findings of	AC	AC East
	68 Dutch ACs	Farnborough	Berkshire
Section A The vision and goals			
An Alzheimer Café is a safe, low threshold,	Agreement on this	same	same
pleasant environment for persons with	definition of AC		
dementia, their family, friends or neighbours,	purpose. No		
[in the presence of a variety of health care	recommendations.		

professionals and members of the local		
Alzheimer Support group]. It offers support		
and information and works towards achieving		
more openness about dementia.		

B The AC guests

Quality Control Criteria for an AC (2005)	Survey Findings of 68 Dutch ACs	AC Farnborough	AC East Berkshire
Section B The AC guests			
1. A minimum of 5% of those present at an AC are persons with dementia.	 - 9% of persons visiting the ACs are persons with dementia - 50% are family members - 19% are volunteer helpers - 22% are involved in another capacity 	16% 57% 8% 19%	18% 55% 12% 14%
	Attendance at the ACs drops as the season progresses [in the winter months]. ACs start with an average of 43 attendees, and this drops to an average of 31, with 37 being the overall average participating annually. On the basis of the mean responses to this evaluation, and extrapolating to these values for all 103 Cafes, 3000 persons with dementia and 16,500	Similar patternattendance drops significantly on evenings of a major sports match. Referrals to the AC were slow the first 3 years; improved with increased awareness of the AC This year 656 persons participated over 11 meetings. (About 95	Same pattern 440
2. Persons with dementia and their family are visible during an AC meetings.	family members of persons with dementia participate in ACs 12% of all interviews at the ACs were with persons with dementia	individuals.) No-one with dementia interviewed during this season but always included in the interactive discussions.	Same
	24% of all interviews included a family member	18%	none yet
	51% of all ACs recorded that persons with dementia participated in the questions or dialogue at the AC	Asking overt questions is rare but persons always participate in response to general questions asked of the audience.	same as Farnborough

3. Those present at an AC also include local caregiving professionals with a variety of backgrounds (a minimum of 3 types). They have local-regional-area knowledge and social knowledge about the impact of dementia.	88% of ACs had at least 3 different types of health care professionals present	100%	100%
4. Caregiving professionals who participate at an AC answer questions and respond to the problems of persons with dementia and their families.	85% of ACs had volunteer helpers participating in responses and reactions to questions	78%	89%
	Recommendations:		
	- extra attention for keeping the AC 'low threshold' and easy to join for persons with dementia	AC held at local community hallworks well.	Same
	- extra attention for the 'surplus value' of interviewing persons with dementia in the AC, and for techniques to help prepare persons to be interviewed	Not required using current interactive discussions	Same.
	- extra attention for the 'surplus value' of making persons with dementia and their families known to the public and the caregivers in the region	Same	Same
	- discussion about the overall impact of the ACs. 2% of the target group is being reached per year. Is that enough? How many persons with dementia and their families is it realistic and possible to reach?	Trying to reach more GP's surgeries and church groups Send out posters, monthly, of next AC	Continuing to build a local contact and referral base. Have started
	 updating the evaluation forms of ACs to more accurately record the different categories of attendees discuss with volunteers the best way to record the various types of attendees 	Send email reminders to those on contact base list Done routinely	Using same categories

C The Leadership for presenting the themed-discussions

Quality Control Criteria for an AC (2005)	Survey Findings of 68 Dutch ACs	AC Farnborough	AC East Berkshire
Section C The Leadership for presenting the themed discussions			
5. The themed discussions are in the hands of a consistent MC-type 'duo'; or pair of presenters/discussion	- 76% of all ACs have a consistent 'duo'	100%	100%

leaders- to ensure familiarity and continuity for the guests (attendees).			10001
6. The themed discussions demonstrate multidisciplinary knowledge about dementia.	- 93% discussion of the themes demonstrated multi-[health care] disciplinary knowledge and input	100%	100%
7. The themed discussions demonstrate practical experience in the interactions with and the guidance of persons with dementia and their family.	- 94%	100%	100%
8. The themed discussions demonstrate good role modeling of interacting with and communicating with persons with dementia.	-83%	100%	100%
	Recommendations:		
	 extra attention for the continuity of the discussion leaders. what are the reasons why some ACs don't work with 'duos'? isn't it necessary to work with a duo, or, is it sometimes not helpful to work with a duo? what do other ACs do to reduce the vulnerability of, and increase the work-capacity of a single discussion leader? 	In the absence of a formal training programme as yet, for AC presenters and interviewers, highly recommend all wanting to start an AC to visit one several times to learn about the presenting details.	Planning more backup
		The current duo system works well- there are a few persons who could take over if necessary.	

D Thematic Content of an AC annual programme

The Themes

Original Dutch AC Theme topics, which follow the dementia process	In the Farnborough AC the original themes are used but other topics have been piloted with good response since 2001 (see below)
What's the matter?	Living with dementia, after hitting
How is dementia diagnosed	the brick wall of the diagnosis and
	breaking through denial
How does memory work and	The range and purpose of human emotions;
what happens in dementia?	Those elicited by: not knowing, getting a diagnosis,
••	looking for a way forward, grieving for changes
	along the way
It's getting a bit much:	Anger and Fear: the lion emotions

feelings of powerlessness and increasing	Why can they get out of control?
communication difficulties.	How to understand them better.
What kind of help is there?	
Who can I turn to for help?	The purpose of communication and the range of
May I say I need help?	communication options.
[Where, When, How to start to get help]	Which are used most/ least?
Day care / residential care	Understanding the grieving process.
How is the decision made?	Understanding different types of guilt.
How does it affect everyone involved?	Hold a 'Guilt competition'.
	Grieving and guilt as separate processes.
	How guilt can delay grieving.
	How to shake guilt off
How do I go on now?	Stress; what is it?
How do people work through their grief	How can it sneak up on you unawares?
and try to go on with life?	Ways of coping with it
	Other topics:
	- Why is it so difficult to break through
	denial sometimes?
	- Understanding behaviour change in light
	of visuoperceptual changes in dementia.
	- Improving the environment to aid vision
	- How does one tell whether 'mistakes' are
	due to normal aging or something else?

Evaluation

Quality Control Criteria for an AC (2005)	Survey Findings of 68 Dutch ACs	AC Farnborough	AC East Berkshire
Section D Content of an annual AC programme			
9. The annual programme is already set out, in large measure, at the start of each year.	- 87% of ACs have formalized programmes of the year's topics ready starting each new AC season	100%	100%
10. The programme follows a year-cycle wherein the themes reflect the dementia process	- 68% of ACs follow that cycle of year themes which match the dementia process (listed above)	100% including the extra themes mentioned above	100%
11. During AC meetings, psycho-social aspects pertaining to dementia receive more attention than the medical aspects	- 80%	- 100%	- 100%
12. The educational part of the ACs, primarily takes place in the form of	- 69% of interviews are with/done by health care professionals	- this year all by professionals	100%
interviews with professionals, persons with dementia and their families, conducted by	- 7% of interviews are of a person with dementia	-by videotape in past years - both interview	0%
the discussion leader.	- 21% of interviews are with a family member	and videotaped in past years	0%
13. The discussion of the evening is usually divided into five half-hour blocks.	- 82% ACs use the recommended times - half hour socialization with the AC guests	No, after 2 years of trying it was changed to the following	- use same format as Farnborough

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	 half hour interview or interactive talk half hour interlude with music half hour session for further questions from the guests half hour further socialization 	format: - 30 mins socializing with refreshments - 30 mins interactive interview / talk / presentation - 20 mins questions - 40 mins socializing and refreshments	
14. At least 70% of the professionals who are used as guest-speakers must work in the local region.	- 76% of guest speakers are from the local region	- all are currently	- all are
	Recommendations:		
	- Uniformity between ACs is relatively large. A small number of ACs are departing from the criteria. It would be good to emphasize the rationale for the 'choice of content themes' at the training days for discussion leaders, and during other times of contact with discussion leaders.	The responses to using the themes have been positive and encouraging.	Same as Farnborough
	- Extra attention for the importance of following the themes of the dementia process during the annual cycle of the AC. Is this really necessary? What are the reasons for not doing so?	We recommend the use of these themes to others, since they seem to work well.	Same
	- The visibility and participation of persons with dementia at ACs is important. The surplus value to AC attendees, of an interview with a family member or a person with dementia, is worth discussing during the Training Days for 'discussion leaders' and volunteers	Previously, interviews have been video-taped because live interviewing was not a possible option for those attending this AC given their verbal abilities and reluctance to speak in public	Neither videotape nor live interviewing has been tried at this AC yet.

E Organization of AC meetings

Quality Control Criteria for an AC (2005)	Survey Findings of 68 Dutch ACs	AC Farnborough	AC East Berkshire
Section E Organization of AC Meetings			
15. An AC has a minimum of 10 yearly meetings	- 72% of ACs hold more 10 or more meetings per year	-11 meetings per year, 2 of which are 'Socials'	- same

	<u> </u>	with a live band	
16. The meetings are held on	-85%	-3 rd Friday of	-4 th Friday of
a fixed day of each month;		month	month
e.g. 1 st Tues. of each month			
17. There is a good sound-	- 86% of AC meetings saw the sound	- 100%, though	- yes
system in the room with	system working satisfactorily	feedback from	
microphones for the		the microphones	
discussion leader, the person		is sometimes a	
being interviewed, and others		problem	
in the room in the event they		r	
wish to ask questions			
18. During the 'non-	- 66% of ACs meetings had 'live	- always have	-same
discussion parts' of the	music'	music CDs for	
evening there is music	- 29% ACs had music on CDs	use	
playing			
19. An 'Information Table'	- 97% of ACs had an 'Information	- always, and	- always
is present in the room with a	Table'	also a	
wide assortment of printed		'Lending library	- same
information and material		provided	
[from the Alzheimer Society		courtesy of the	
and other reputable, known		local Alz. Soc.	
sources], aimed at the		Branch.)	
average person who would			
attend an AC			
20. The Information Table is	- 96%	- always	-same
manned by one or more		- also display	
volunteers from the		artwork from the	
Alzheimer Society		children of local	
,		schools with	
		their version of	
		the UK AC logo:	
		'All in the same	
		boat'	
21. The room chosen to hold	- 46% of ACs were held at Residential	- at a local	- at a local
an AC in, is in an	or Nursing Care Homes	community	community
environment which is as non-	ACs held in these Care settings had	centre	centre
threatening as possible (low	an average of 7% attendees with		
threshold) for persons in the	dementia		
beginning stages of dementia	ACs held in other locations had 11%		
or memory difficulties. A	persons with dementia		
nursing home is not the most			
appropriate place.			
22. Attending an AC is free-	- 56% of ACs do not ask for financial	- never asked for	- same as
of-charge for guests. No	contributions for their expenses	but a raffle is	Farnborough
donations are asked for		held at the social	
during the AC		evenings to pay	
		for live band	
23. Volunteers greet and	- 96%	- 100%	- 100%
attend to guests on arrival, on			
leaving, and if they are sad,			
restless, or don't know what			
to do with the information			
communicated			
24. An AC is organized	- 76% have this mixture	- steering	- steering
together with the local	- those professionals active include:	committee has an	committee
division of the Alzheimer	care assistants, nurses, supportive	Alzheimer	composition
Society and volunteers from a	family carers, Carer support workers,	Society rep and 2	being
minimum of 3 different	social workers, OTs, physiotherapists,	other	reevaluated
professional sectors	speech and language therapists,	professionals	currently to
	psychologists, doctors, Nursing Home		include more

	Lagran and the		
	Medicine Specialists		representatives from the AS. y Branch groups, and other health care professionals
25. An AC is organized by a steering committee or workgroup, where in all persons [specified in point 24], actively participate	-78% have a steering committee comprised of a fixed number of persons who organize the meetings .	Yes, and all participate actively	Not fully yet
26. A designated contact person at the Alzheimer Society will be responsible to appoint a fixed contact person, local to an AC, on behalf of the AS to the steering committee.	- 96% of ACs have an permanent 'contact person' appointed by the local Alzheimer Society Branch group	- yes	- yes
27. The steering committee of an AC is responsible for the quality of an AC and accepts responsibility for enforcing the QCC	- 71% of the organizing partners actively participates in the work group	- yes- always	- not yet
28. The logo of the Alzheimer Society is clearly visible in all information about the AC, Public Relations events, in the annual AC programme, and in general.	- 84% of ACs had folders and the logo of the Dutch Alzheimer Society visible	always present	always present
29. The steering committee undertakes at least 2 activities per year to attract regional press publicity to promote the AC.	- 82% of ACs hold/ are involved in, at least 2 activities per year to get the attention of the local press	-yes; usually reporting a fund- raising efforts or the social evenings	- same
	- extra attention could be given to inviting and working with Pastoral Care Workers and other professionals who have been less present at the ACS. This could be done at the National Annual Meeting extra attention could be given to 'press publicity for ACs' at the National Annual Meeting the use of music at the ACs is intended to make such evenings pleasant, not just informative. It helps to generate amusement and frame the different sections of the evening. Is it too difficult for some ACs to organize music, or do they not find it important? - The 'professional input' listed as	- GPs, Social workers/ care managers rarely attend ACs - chaplains or pastoral care workers have never attended but have had staff from local care homes and students of health care professions present Need to find a committed, consistent UK forum to increase the publicity for the ACs that	Have found that 'Music for Hospitals'(?) is a good source of live music
	being 'most missed' by those organizing ACs, were Pastoral Care	exist nationally, to link them, and	

Workers, home care workers, local	find an umbrella
hospital staff, day care centre staff,	organization to
nursing home staff and the GP	publicize them,
-	help set them up,
	offer training,
	and become
	involved in QCC
	evaluations.

F Evaluation of the meetings

Quality Control Criteria for an AC (2005)	Survey Findings of 68 Dutch ACs	AC Farnborough	AC East Berkshire
Section F Evaluation of the meetings		Taribor ough	Del Ramite
30. Guests at an AC are always invited to evaluate the AC in verbal or written form [e.g. in a comments book]	- 75% of ACs evaluate each AC evening. This is done both by asking for individual and collective feedback, and through providing a comment book or evaluation forms	- evaluations have always been done after each AC - a 'visitors comment book' is on the registration table	- evaluations done, but have been standardized recently
31. An estimate of the numbers of guests is made at each meeting	[persons with dementia, family members, friends, caregivers, others] - 10% of ACs have only started evaluating their ACS as a result of this Evaluation Survey, which now constitutes their first evaluation of their AC, and which they can build upon	yes, these and also categories: Carers Former Carers, Volunteers, Newcomers, Professionals and persons interested in starting an AC	yes
atmosphere, content, discussions and Information Table at the AC, at least once every two or three years	- 66% of ACs have already evaluated the functioning of their AC in a previous year	after each meeting as part of current evaluation	- in progress
33. The AC steering committee self-evaluates the AC annually using these QCC and sends their evaluation to the appropriate person at the Alzheimer Society	- 2 ACs said that they did not wish to evaluate their AC, but did fill out the Evaluation Surveys questions It is possible that among the ACs who did not participate in this first Evaluation Study of ACs, there are others who see 'evaluating' as a tiresome chore	Will continue to do so- however, there is no designated person at the National Alz. Soc. yet to send them to.	Will continue to do so
	At the next National Meeting, discuss ways to make evaluating ACs easier and more informative for those of the Dutch Alzheimer Society and their	It would be helpful and interesting to know how other ACs in the UK evaluate their	

partners in the AC steering committees.	groups to understand what types of regional adaptations work best in given
	best in given
	areas, and why.

Summary conclusions about the first evaluation of two UK ACs against the QCC

The vision and goals of the AC concept, as guided by the new QCC seem readily achievable with a good steering committee, the contributions of various health care professionals, and new inflow (referrals of new persons with dementia from a variety of local professionals, care services and care providers).

Persons with dementia are present, and participate well at ACs, mostly in the form of spontaneous comments during interactive discussions of themed topics. Interviews with persons with dementia have only been done in past years by videotape and shown at the AC, but not live. Perhaps now that the AC is better known, and persons are more familiar with how it operates it would be possible to see if there is interest in doing a live interview with persons with dementia at the AC.

Attendance does dwindle somewhat throughout the year, particularly in the dark winter months, but there is a constant new influx of guests. Some family members have continued to attend the Farnborough AC since it opened in 2000, despite the death of their own family member. Their experience is invaluable for welcoming, socializing with and supporting newcomers. Volunteers are present and active at all AC meetings; their help is pivotal to holding an AC.

The help of representatives from the local AS branch groups has been vital for the ACs. It has been difficult to attract some professionals to the ACs, possibly because they are held on Friday evenings. It would be very good to see more GPs, geriatricians, old age psychiatrists, psychologists, social workers and care managers at the ACs. Pastoral care workers and chaplains have never attended yet, and their involvement would be much welcomed.

Another type of quality control evaluation

The QCC are only one type of evaluation. The comments in the Visitors' Book provide another type of quality control evidence of the value of an AC. For example:

Excerpts from UK AC Visitors Comment books

You are a "lighthouse" that guides this boat into calmer waters and safe harbour. We will help rowing this boat!" - Carer, Fleet

It's magic to come here every month - Person with dementia, Aldershot

Great atmosphere, everyone together sharing feelings and experiences. Thank you - Alzheimer's Society, Oxford

Incredible welcome - both people and venue so much thought was put into this aspect, genuine attention to detail - candles, table layout, people available at start and in breaks. Activities Coordinator, EMI home, Farnborough

The Cafe has been our saving grace, I don't know how we would have coped without all the support and help we have found here - Carer, Fleet

This is our first visit and I must say we were very impressed! The atmosphere is so warm and friendly, Very interesting talk, it helped us recognise that we are not alone. Carer, Church Crookham

Thank you for a very informative and friendly evening. My parents seem to have enjoyed the evening. As I speak my mother (the Carer) has moved onto another table and is chatting happily away. Carer - Hawley

Very useful and informative as a visiting professional - OT, Surrey Adult Services

I really enjoyed the evening and found the talk very interesting. Carer, Hawley

It was a fantastic evening - person with dementia, Aldershot

It was great to see so many people relaxed and having a good time. A wonderful place for people to get together and talk about their experiences. The talk was very interactive and so enjoyable. Wonderful photography. I will spread the work to everyone in Central Region and the National office. Alzheimer's Society.

I have been coming to the meetings for a year and have found them all of a great help to me. Carer

The Cafe is an excellent institution, bringing together people with similar dementia caring problems who can draw upon each other's experiences and also benefit from professional talks and advice - a must for funding! Carer, Sandhurst.

I find the cafe relaxing, interesting and extremely helpful - such support is very welcome. Carer, The Sands

We have come from Chiswick to understand more about how an Alzheimer Cafe might support people with dementia and their carers. The warm welcome, information-sharing and guest speaker were all a real surprise in terms of openness and enthusiasm. We'd like to keep in contact. Professionals interested in starting an Alzheimer Cafe, Chiswick

I was so impressed by our first visit and lovely welcome at the Alzheimer Cafe UK. It's almost impossible to find the proper words in trying to say thank you to everyone who took such care. Carer, Farnborough.

Very useful evening, helpful to understand the workings of the Day Hospital. Video was fascinating. The most useful thing for all (for me as a GP) however, is talking to people and learning of their experiences. GP, Farnborough.

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