The role of dementia champion in dementia care: its aspirations, development and training needs (innovative practice)

ABSTRACT

Background: The conceptualisation and development of the role of Dementia Champions in clinical practice is ongoing, and dementia specific training has a significant impact on the scope of the role. **Aim:** This survey aimed to elicit Dementia Champions' views on their role and associated training needs. **Methods:** Data were collected via an online survey. **Findings:** Thirty four of 188 dementia champions (response rate 18%) participated. Most perceived dementia awareness training as useful, but limited. Areas suggested for further development were context specific skills training, education programmes that were formally recognised, and clarification around the expectations of the role. **Conclusion:** Expectations of 'champion roles' in dementia need to be re-visited, specifically in relation to the remit of the role and the level of education, preparation and support required for Dementia Champions to become change agents in dementia care.

Key words: Dementia champions, dementia care, education, training

INTRODUCTION AND BACKGROUND

The Dementia Champion Community of Practice (DEMCoP) project was designed to create a shared focus for the role of Dementia Champions in the East of England and to identify priorities for education and training. Phase one of the DEMCoP project concentrated on creating infrastructures that would connect Dementia Champions (Mayrhofer, Goodman, & Holman, 2015). As part of phase two the project used an online survey to elicit Dementia Champions' perceptions of their role, its remit, and perceived training needs. Specifically, the survey aimed to establish:

- The professional roles held by dementia champions and whether or not the Dementia Champion role was formally recognised
- What the Dementia Champion role entailed and if dementia champion specific responsibilities were reflected in job specifications
- The various clinical contexts that Dementia Champions worked in
- Dementia Champions' perception of the adequacy and applicability of dementia education and training

This paper considers the level of preparation and dementia specific education and training Dementia Champions received.

METHODS

Data were collected via an on-line survey (Bristol Online Surveys) that was developed, piloted and launched in January 2015. The survey web-link was emailed to Dementia Champions who were already on the DEMCoP data base held by the University of Hertfordshire. This data base included the names and contact details of people who were identified by their organisations as Dementia Champions, and email addresses of a smaller self-selected group who had submitted a request to join DEMCoP. The survey consisted of 25 questions which were a mix of multiple choice, multiple answer, and text questions. The survey took 10 minutes to complete. It remained open for one month and weekly reminders were sent to potential respondents to encourage participation.

FINDINGS

Of the 224 emails sent to Dementia Champions 36 (16%) were returned as delivery failures. Of the 188 potential respondents 35 participated in the survey, one of whom was not a Dementia Champion and was excluded. This left 34 valid responses, a response rate of 18%. Whilst this was disappointing, the range of clinical areas

represented (n=7) and different job titles (n=24) enabled the role and clinical context of Dementia Champion's work and range of experience to be captured.

Sample characteristics

Nearly all (94%) of the 34 respondents were female. Fifty nine percent were aged between 51 and 60 years. Dementia Champions held professional roles as practitioners, for example nurses, therapists and emergency staff (38%), senior practitioners (32%), managers (18%), and support staff (6%). Two respondents did not disclose their role to maintain confidentiality. Of 34 respondents 27 worked in four NHS Trusts, six worked in two Social Care organisations in the community and in day services, and one respondent did not disclose their area of work.

The Dementia Champion role and its remit

The remit and foci of the Dementia Champion role varied. Of 34 respondents, 74% disseminated dementia related information to immediate colleagues, 38% advised staff on how to support people living with dementia, 24% were a 'named expert', and 21% were responsible for training staff in dementia care. The majority of participants who held Dementia Champions roles were practitioners and senior practitioners, some of whom also held highly specialised nursing roles. The clinical areas in which Dementia Champions worked are shown in Table 1.

Table 1: Clinical areas of work of Dementia Champions

Clinical area	NHS Trust N (%)	Social Care N (%)	Total N (%)
Acute	14 (52)	0	14 (43)
Community	5 (18)	2 (33)	7 (21)
Mental Health	1 (4)	0	1 (3)
Primary Care	1 (4)	0	1 (3)
Social care / day services	0	4 (67)	4 (12)
Outpatients	5 (18)	0	5 (15)
Theatre	1 (4)	0	1 (3)
Total	**27 (100)**	**6 (100)**	**33 (100)**

Six of the 34 respondents had intensive contact with people living with dementia both in Acute NHS Trusts and in Social Care. The majority of Dementia Champions reported occasional encounters with people living with dementia. Of 34 respondents, 21 (62%) had their Dementia Champion role formally recognised. Six of them were given a job specification outlining what the expectations of this role were.

Dementia specific training

As indicated in Table 2, training input varied. Most Dementia Champions (53%) had received one full day of training, followed by 26% who had received training for half a day. Four respondents had completed a short course without accreditation or qualification and three completed a course that was linked to an award structure. Three Dementia Champions had not received any training.

Table 2: Dementia specific education and training received*

	N (%)
Full day training	18 (53)
1/2day training	9 (26)
Short course without accreditation / qualification	4 (12)
Course linked to dementia qualification (award/certificate/diploma)	3 (9)
No training received	3 (9)
Other	5 (15)

** Based on 34 replies. Percentages do not sum to 100 as multiple options could be selected.*

The most beneficial aspect of training received was skills-building that focused on the minimisation of distress and promoted patient safety. Examples included skills in how to reduce stress in people with dementia and their family carers or paid carers, safeguarding and applying the Mental Capacity Act 2005 (UK-Government, 2005), and workplace specific interventions in dementia care. Also highlighted as helpful was learning about the differences between delirium, depression and dementia, and understanding how cognitive function changes with dementia. Areas identified as requiring further input were around better knowledge of referral processes for people living with dementia and the coordination of community based care.

Perceived adequacy of training

Of 34 respondents, 20 (59%) thought that the dementia education and training received were adequate for the job they did, but 14 (41%) stated that training had not addressed the dementia related challenges they encountered in daily practice. Perceived training adequacy was not significantly associated with position, job title, or length of time in current job. However, there was a statistically significant association between perceived training adequacy and the clinical areas Dementia Champions worked in ($p=0.019$, Fisher's exact test). Whilst most respondents working in the community and in Social Care thought that training had been adequate, the majority of respondents (71%) working in acute care thought it had been inadequate. This is shown in Table 3.

Table 3: Perceived training adequacy by clinical area

		Clinical area of work							
		Acute	Community	Mental Health	Primary Care	Social care/ day services	Out-patient	Theatre	**Total**
Training adequate	**Yes**	4	6	1	1	3	5	0	20
	No	10	2	0	0	1	0	1	14
Total		**14**	**8**	**1**	**1**	**4**	**5**	**1**	**34**

There was also a statistically significant association between perceived training adequacy and the organisations that Dementia Champions worked for ($p=0.036$, Fisher's exact test). As indicated in Table 4, in Trust A only five (36%) Dementia Champions thought that training had been adequate, in Trust B four (67%) Dementia Champions, whilst in Trust C five (83%) Dementia Champions thought that their training had been sufficient.

Table 4: Perceived training adequacy by organisation

		Organisation							
		NHS Trust A	NHS Trust B	NHS Trust C	NHS Trust D	Social Care A	Social Care B	Undisclosed	**Total**
Training adequate	**Yes**	5	4	5	1	5	0	0	20
	No	9	2	1	0	0	1	1	14
Total		**14**	**6**	**6**	**1**	**5**	**1**	**1**	**34**

Of the 14 respondents who perceived training as inadequate, 10 (71%) felt the need for training that was more specialised. They wanted knowledge in 'specialist' topics that were relevant to their particular job role, experiential learning, and a recognised qualification in dementia care. Interestingly, even those who thought that training had been adequate reported the need for more in-depth training on topics that were discipline specific.

Appropriateness of the term Dementia Champion

Of 32 respondents, less than half (44%) thought that the term 'Dementia Champion' was an appropriate reflection of their dementia responsibilities. As one respondent remarked,

> "*I have noticed that people smile when they hear the word 'champion' in relation to dementia. To be honest, I would like a definition of the term*" [RES10].

Another respondent stated

> "*…I just say that I am dementia trained, I never say 'champion' [RES19]*.

A thoughtful observation came from one respondent in the community about the implications of giving titles, which are not tied to qualifications:

"…[the word] *champion is being used to allow staff to develop skills without any formal recognition of the extra knowledge, ability, responsibility that goes with that. This is true not just with dementia but with a range of champion functions (we use safe-guarding, MCA [Mental Capacity Act], pressure ulcer, to name a few). Whilst this is a great career development I do worry that it represents a move towards more and more complex functions being undertaken by increasingly low staff grades" [RES30].*

DISCUSSION

Survey results show that Dementia Champions hold a variety of professional and specialist roles as clinical support staff, practitioners, senior practitioners and managers in settings as diverse as Acute Trusts, Community Trusts and Social Care Services. Only a few respondents were given formal job-descriptions. Expectations of the role are therefore not always clear and the title does not sit easily with some of the respondents. There are only a few definitions of a Dementia Champion and they are aspirational, for example:

"… a dementia champion is someone with excellent knowledge and skills in the care of people with dementia. They are an advocate for people with dementia and a source of information and support for co-workers. They will have an understanding of the change process from a theoretical and practical perspective. A champion is self-motivated, motivates others and acts as a role model in the delivery of person centred care. A champion is someone that has the leadership qualities and communication skills to act as a change agent" (Dublin City University, 2015).

The idea of a Dementia Champion being a change agent is also emphasised in a training programme rolled out by the National Health Service (NHS) Scotland (Banks et al., 2014; NHS Scotland, 2015), which specifically prepares participants to become

‘agents of change’. The participants in this survey did not receive input on how to achieve changes in practice, or what might be required of an agent of change.

The preparation that the majority had received was foundational in content (NHS Health Education England and Skills for Health, 2015), and survey respondents were interested in receiving further education and training that was context sensitive, formally recognised, and that equipped them to have a system level as well as a practice level impact.

The finding that the majority of respondents either did not use the title of Champion or were ambivalent about what it represented is interesting. The fact that a Dementia Champion is one of many champion roles held by a range of practitioners risks diluting its impact and significance for the care of people living with dementia.

If prime-ministerial ambitions for “…England to be the best country in the world for dementia care and support by 2020” (Department of Health, 2015) are to be realised, then there is a need for the existing cohorts of Dementia Champions and those that join them to be identified and developed across health and social care on an ongoing basis (NHS Scotland, 2015) (Ellison, Watt, & Christie, 2014). Dementia Champions could contribute significantly to the overall supply of dementia care staff. Structures for the longer-term development of dementia care staff need to be established at the strategic/macro level (Vollmar et al., 2014).

LIMITATIONS

The low response rate and consequently small sample size constitutes a limitation. However, the sample was composed of practitioners, senior practitioners and managers across health and social care and represented Dementia Champions’ roles in Acute Trusts, Community Trusts and in Social Care at a regional level.

CONCLUSION

There is potential in the scope of the Dementia Champion role and there is a window of opportunity to link Health Education England competencies and training to qualification structures that offer recognised pathways in dementia care (NHS Health Education England and Skills for Health, 2015). There was some evidence of Dementia Champions being the means for knowledge sharing and dissemination of good practice. However, the lack of formal organisational endorsement and recognition coupled with limited access to a qualification or remuneration structures in dementia care risk limiting the long term impact these roles could have.

Conflict of interest

None declared

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