

JEWISH CARE

WORKING WITH



PROJECT FUNDED BY THE KING'S FUND

IMPROVING END OF LIFE CARE FOR PEOPLE WITH ADVANCED DEMENTIA

**REPORT ON A 3-YEAR PRACTICE
BASED PROJECT ASSESSING
THE IMPACT OF END OF LIFE TRAINING 2012**

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SUMMARY

This joint Jewish Care study funded by the King's Fund aimed to put in place and evaluate an intervention to improve end of life experience of residents, with advanced dementia, as well as reducing the stress for staff. We planned the study because there were no end of life interventions for people with dementia, which have both reduced hospital deaths or increased family satisfaction.

The study took place in Lady Sarah Cohen House, a Jewish Care nursing home in North London with 120 beds over three floors. The intervention was a 10-session interactive programme devised, implemented and made into a manual, by a consultant physician (JM) and Jewish Care managers (HJ, NC, GW). The programme took into account the challenges in delivering end of life care which were discussed by staff in the pre-intervention interviews.

The training programme topics were: The challenges of dementia end of life care; The physical process and symptoms of end of life; Emotional and psychological needs at end of life; Planning for end of life care; (Advance) Care planning and communication with residents and relatives; Religion and spirituality at end of life; Holistic care for people with dementia at the end of life and finally a summarising and reflective session.

The programme emphasised preferred place of care, how to have difficult conversations, structured listening, communication, observation, kindness, empathy and compassion. It included role-playing around advance wishes and care plans. In addition, there was a catch up day for staff who had been unable to attend or who had missed a significant number of the sessions, and a separate session for senior staff on completing an advanced wishes form and talking to relatives. Each session was given four times to ensure all staff could attend.

All care was personalised according to the advance care wishes from residents and their relatives.

We examined the results using case notes and interviews with the relatives of the 30 people with dementia who were resident in the home for more than one month and died in the year before the intervention and their 29 counterparts who had died in the year after its implementation; and the care staff in the home. The process evaluation is presented in detail in the main paper.

The intervention was successful in quantitative and qualitative terms. The numbers were small and not all numerical changes were statistically significant.

1. After the intervention more people with dementia died in the care homes compared to hospital (76% after 47% before; $p < 0.02$).
2. A greater number of residents had advance wishes in their notes after the intervention than before. (73% versus 14%; $p < 0.001$).
3. In contrast to before the intervention, all advance wishes were adhered to (100% versus 71%; $p < 0.04$).
4. Median days in hospital in the three months prior to death fell from 4 (pre-intervention) to 1.25 post intervention. There was a wide range of days in hospital (0-34 pre-intervention and 0-68 post intervention) and this change was not statistically significant.
5. Interviews with a small number of relatives after they had been bereaved suggested they were less stressed than prior to the intervention (GHQ score after fell from 3.5 to 1.5).
6. The quality of the end of life of their relative had been improved. (QOL AD 21 versus 18)
7. Relatives were pleased with the end of life care after the intervention. This was in contrast to before. Changes were in the right direction with families reported being consulted more about decisions and being supported more. Medical care and symptom and pain was either unchanged or improved.

- 8.** Staff felt better equipped to deal with the increasing frailty of the residents.
- 9.** Relatives understood issues around symptom control, they felt that staff recognise when someone is reaching the end of their life and supported them in making decisions. They thought that advance planning was necessary because of unpredictability of death and because relatives could not make their own decisions and the home staff would guide them.
- 10.** Following the intervention, staff exhibited a better understanding of the management of distress and pain in older people with dementia.
- 11.** Staff also found it easier to discuss death and dying with relatives, and therefore became more confident and comfortable with end of life planning and communication.
- 12.** Staff were less worried about being blamed because they were following advanced wishes.
- 13.** Staff felt the training has been helpful and they have a greater understanding of end of life care and advanced wishes.

CHAPTER 1: INTRODUCTION

This report describes the End of Life in Advanced Dementia (ELCAD) project, a 3- year practice based study funded by the King's Fund and carried out in a large Jewish Care nursing home in collaboration with University College London (UCL) and consultant in Geriatric Medicine, Dr Jackie Morris.

BACKGROUND

One in three adults die with dementia; often receiving poorer quality care than those who are cognitively intact (Lawrence et al., 2011; Sampson et al., 2011a). The Dementia strategy (DoH 2009) and End of Life strategy (DoH 2008) recognise the continuing trend of growth in the population of older people, particularly of 85 years of age and older, and therefore the anticipated growth in the number of people with dementia and the number of deaths of older people. More significantly these strategies recognise and advocate more choice and control for older people in making decisions about their future care. The early diagnosis of dementia and the importance of creating advanced care plans and or advance statements became recognised and recommended as ways of enabling people to pre-empt situations where lack of capacity leads to lack of control over ones life and care choices. Advanced dementia was also increasingly recognised as a terminal disease. (Mitchell 2001& 2009)

Internationally most of those dying with dementia are residents in care homes (Houttekier et al., 2010; Goodman et al., 2010). However, as people with advanced dementia often experience sudden acute very serious medical problems, even if they and their family would prefer them to remain at home, they are transferred to hospital, as advance decisions or wishes about end of life care have not been made explicit or are not implemented (Robinson et al., 2012; Dening et al., 2011; Livingston et al., 2012). This is partly because they lack capacity to make their own decisions about what interventions they want and where they wish to experience the end of life and families find many difficulties in making these decisions for them(Livingston et al., 2010).

Advance care wishes or plans about what treatments are wanted and in which circumstances are difficult to make once in hospital and interventions to increase their use should ideally take place earlier (Sampson et al., 2011b). Once in hospital, people with dementia frequently experience uncomfortable interventions without demonstrable benefit which fail to improve survival times(Sampson, 2010) and may die within hours in a strange place with professionals who do not understand their needs for pain relief or comfort. '

It would therefore be preferable if care homes helped families decide about advanced care wishes for end of life decisions early and provided end of life care at the care home if appropriate.

Identified barriers to improving end of life care in dementia in care homes and delivering care in line with residents' and families' wishes, have included difficulties in staff communicating with each other and with families about imminent death, lack of confidence of staff, concern amongst professional staff that not sending someone to hospital may result in them being blamed and family and professional carers differing culturally and ethnically (Dening et al., ; Livingston et al., 2012).

There are currently no interventions for end of life care for people with moderate or severe dementia, the typical residents of care homes, which have improved satisfaction of families or residents with end of life care planning (van der Steen et al., ; Robinson et al., 2012). Two studies which focussed on increasing advanced care planning in care home residents, including people with dementia, have achieved increases in the number of documented advance care plans and reduced hospitalisation but place of death is not reported (Robinson et al., Deming et al., 2011).

The introduction of the Liverpool Care Pathway and the Gold Standard Framework were developed to improve end of life and palliative care in a holistic and person and relationship centred manner. The National End of Life Care Programme published the core record content to support the provision of high-quality coordinated care at the end of life, on 20th March 2012 after the intervention was finished but very much in line with the principles of the project: <http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard>

In this study we delivered and evaluated a programme for care home staff to improve end of life care for people with dementia. The programme was designed to tackle the attitudinal barriers as well as give staff the practical tools and knowledge. It also needed to understand the varying degrees of literacy and comprehension amongst the staff group.

We aimed to enable staff to work with families to plan, document and implement legal end of life advanced care plans for people with dementia in care homes in order to improve end of life care.

SETTING

Jewish Care, a charity providing a range of social care services to the Jewish community, faced similar challenges. Senior Jewish Care staff increasingly understood that there was a need to encourage, facilitate and support staff to demonstrate empathy and compassion in difficult challenging circumstances. They recognised the need for organisations to continually improve, change and develop practice using clinical governance to help all staff to stand back and challenge traditional custom and practice. In 2008, the average age on admission to a Jewish Care care home (total capacity of 771 beds) was 88 years (compared to 78 years in 1998) and a growth of number of deaths from 18% in 1998 to 25% in 2008. Furthermore, in 2008 over 40% of people who died whilst residing in a Jewish Care home, died in hospital and although this number was somewhat lower in the nursing homes (33%) and compared favourably against the national average of 58% it indicated that improvements in the provision of end of life care were needed.

The project was carried out at Jewish Care's Lady Sarah Cohen House, a large nursing home providing personal and nursing care to Jewish people with and without dementia.

The home occupies a large building where 120 residents occupy 3 floors, each with its own staff group of nurses, carers, activities organisers, alongside the manager and housekeeping staff, as well as volunteers. In addition, there is a central administration team, registered manager and a holistic therapist as well as a physiotherapy team, for the whole home.

At the time of the project, the home employed 30 nurses and 60 carers in addition to the management of the home. The staff in the home are mostly not Jewish and of varied ethnicity and religions. The home operates 12-hour shifts (8am-8pm and 8pm-8am) with 15 minutes handover overlap at the end / beginning of each shift. During each day shift there are 9 nurses and 21 carers on duty and at night there are 6 nurses and 12 carers on duty.

One of the floors in the home specialises in care for people with very advanced dementia, often with very challenging behaviours. The other floors provide nursing care to a mix of people with and without dementia. Frailty levels are generally very high, with the average age on admission in 2009 of nearly 88 years.

The home is registered with a local practice of GPs who provide GP services to the residents and visiting the home for weekly surgeries as well as home visits when required.

RATIONALE FOR THE PROJECT

In addition to the evidence of growing demand for end of life care in our care and nursing homes for an increasingly old and frail population, anecdotal evidence indicated that:

- Staff lacked the knowledge, practice, confidence and support to deliver the end of life care as outlined in the End of Life strategy.
- The experience of people dying whilst in Jewish Care homes and their families, was varied and often marred by last minute changes in care, crisis intervention and unplanned hospitalisations (leading to death in hospital as a consequence).
- Staff experienced high stress levels due to the above and no mechanisms for support or reflection were in place.

A multi-cultural non-Jewish care force providing care for an all Jewish client group, may have contributed to the 'tensions' around provisions of end of life care.

Communication between staff, clients and their families was made more difficult when older people faced their own problems with language and understanding because of their diseases as well as hearing and visual problems. The decision making process became more problematic when a person no longer had capacity to make decisions. This then became the shared responsibility of the care team and the person's family.

The organisation's strong commitment to continuous learning and development of services led to the collaboration with Dr Jacqueline Morris and Professor Gill Livingston of UCL, to address the challenges identified.

The application to the King's Fund in 2008 was for a 3 year study to be carried out in Jewish Care's largest nursing home, providing personal and nursing care to 120 people, many of whom have advanced dementia.

AIMS AND OBJECTIVES

The overall aim of the project was to improve the quality of end of life care which is provided to people with advanced dementia in care homes. In order to achieve this, the study set out to:

- Develop and introduce a structured end of life care programme for people with dementia in care homes and their relatives, which complemented the Gold Standard Framework.
- Enable staff to develop their skills, knowledge and understanding of dementia and end of life care in the context of the Jewish way of life and attitudes to death and dying, via a comprehensive learning programme and the development of links and network for support and collaborative working with external agencies such as GPs, palliative care teams and local hospices and hospitals.
- Evaluate the implementation and impact of the above interventions on the people receiving end of life care in the home, their relatives and staff.

The objectives of the study were:

- To increase the quality of end of life experience for the people receiving the care and their relatives and to reduce the anxiety and stress they may experience during this period.
- To increase staff confidence and their ability to deliver high quality end of life care that reflects the wishes and preferences of the person receiving the care and their relatives, as expressed in the care plan.
- To understand the impact (if any) of differences in cultural and religious attitudes towards end of life care, death and dying, between the (non-Jewish) staff and the (Jewish) recipients of care and their families.

PROJECT STRUCTURE

The 3.5 year project which commenced in March 2009, consisted of two main components, namely the development and delivery of a staff development programme; and the evaluation of the impact that this intervention had on the practice and therefore on the experience of people receiving the care, their families and staff.

These components were undertaken in three stages:

Stage 1 – Pre intervention: evaluation and development of the training programme (the intervention)

During this stage the 'experiences' of residents, relatives and staff are sought via quantitative and qualitative tools and analysed for comparison with findings of repeat measures after intervention (stage 3). This was to be carried out by a researcher under the guidance of Prof. Gill Livingston of University College London.

At the same time a comprehensive training programme for the staff was being developed by Dr Jackie Morris and a team of Jewish Care senior managers.

Stage 2 – Intervention: Training of staff and implementation of End of Life care practice for people with advanced dementia.

Delivering the training programme which explores a wide range of topics related to dementia, end of life care, communication and reflection, medical and holistic interventions and others. The 10 session training was delivered over a 12 months period during which time most of the 130 strong staff team were able to attend between 3 and 10 of the sessions led by Dr Jackie Morris and Jewish Care professionals.

Stage 3 – Post intervention: evaluation and dissemination

Following the completion of the training programme, a re evaluation of the experiences of people receiving end of life care, their relatives and staff was undertaken by the UCL team in order to assess the impact of the training programme and whether it had led to a positive change in practice which in turn has improved the outcomes and experience of stakeholders.

In designing all stages of the project, special consideration was given to the sensitivities of such an 'intrusion' to the life at the home, both at the beginning of the programme as well as at the end. Care was taken in planning the introduction of the key external members of the project group to the staff and others and reassurance that they were not 'observers for the management' but 'independent supporters' for the team. Towards the end of the project, an exit strategy that will support ongoing development was also considered and implemented.

PROJECT MANAGEMENT

The management of the project presented its own challenges, and it was important to recognise these at the outset, and put into place measures that ensured that the project was delivered and completed according to plan (or any agreed changes).

The factors which challenged the team were identified as:

- A multi-disciplinary and cross-agency partnership consisting of academics, funders and professionals.
- Finite funds and resources, and a strict timeframe.
- Introducing a comprehensive and lengthy learning programme to an audience of varied learning and literacy skills and capabilities.

- Introducing a research study into a very busy nursing home environment.
- Dealing with a sensitive subject which is usually not talked about openly.
- Seeking the open views and feelings of those who may feel apprehensive of sharing this.

In order to create platforms in which the project team could debate these challenges and gain advice and support the following forums were put in place:

Project Management Group - The role of this group was to consider operational issues of the project, as well as monitor planning and progress and any issues of concern or difficulties encountered. The group met quarterly and produced a progress report for the steering group (see below) on a six monthly basis.

Members of the project management group were:

The project lead, intervention lead, researcher, registered manager and care manager of the home, relatives' representative and a member of the Jewish Care dementia and disability team.

Steering Group - The role of this group was to keep an overview of the project and monitor its progress in relation to the original funding agreement. It was also a platform for considering any difficulties encountered by the project group and offering advice where appropriate. The group met twice a year and were given a report and presentation of the project progress by the project lead who attended the meetings. It consists of:

The assistant director of care services in Jewish Care who was the project sponsor, representative of the King's Fund, service manager of dementia services in Jewish Care and a volunteer with experience of palliative care services.

CHAPTER 2: THE INTERVENTION

SHAPING THE INTERVENTION

At Lady Sarah Cohen House the approach to end of life care in the home was reactive rather than pre-planned and the pre-planning that did occur was not consistently recorded. Care was focused on the presenting condition or symptom. Behavioural problems were sometimes attributed to dementia rather than physical discomfort or pain or as personality rather than dementia. Few really detailed life histories were taken from family members leading to less effective communication between nursing staff, GPs and some families.

Staff could often appear to be defensive and families often underestimated the affection they had for the residents. Staff felt defensive and frightened that they might be blamed when things went wrong or a person died. Some were of the opinion that the relatives failed to understand dementia and how it affected people.

There was a belief that hospitals were the appropriate place for people whose health was failing. Some nurses, care home staff, and relatives felt unsupported with the process of dying. The relatives also thought they were ill informed about choices. At times the communication between the GPs and staff in the home was strained due to the lack of clear, shared terminologies. The training and support to care home staff did not fully address the staff's anxiety caring for people with increasingly high or complex care needs including end of life care and the number of people being admitted who were close to death. The floor managers reported that the training they had received was fragmented and did not necessarily follow a logical order.

INTERVENTION METHODS

DISCUSSIONS WITH MANAGERS, NURSING STAFF, AND GENERAL PRACTITIONERS

It was decided that LSCH would delay joining the Gold Standard Framework until the following year to synchronise with the project.

The intervention lead met the home's management team, project manager as well as the GPs prior to launching the programme.

These discussions highlighted some of the issues and barriers that key personnel perceived or experienced in relation to end of life care for people with advanced dementia. These discussions informed the intervention lead as to the content and delivery method of the programme.

These discussions were invaluable and revealed the fragmented approach to end of life care that existed at the home at the time. There was no structured or regular multi-disciplinary approach to planning end of life care and to pain management, and recording of end of life wishes in particular. The General Practitioners who provided GP services to the home did not always feel part of the team and were concerned about the amount of time that the consultant physician would need to work with them on the project as they felt pressurised with their current caseloads, particularly as they felt there had been an increase in complex care needs of new admissions. Dementia was not seen as a terminal illness and pain management was variable. There was poor communication between staff and relatives and both groups viewed one another as 'problems'.

These findings demonstrated that there was a need to develop better teamwork, better relationships between nurses and GPs and improved communication between all members of staff with relatives. There was also a need to change the culture around death and dying and to enable and encourage staff to think about what a good death meant to them, the people they cared for and their relatives. Following this the staff needed to be able to stop thinking of death as a taboo word and start being able to hold difficult conversations with families about advanced wishes and cardiopulmonary resuscitation.

THE TRAINING PROGRAMME:

The teaching programme was developed between June 2009 – August 2009 having taken account of all these discussions and observations. It consisted of three phases, a preliminary stage; a 10-session course; a revision stage.

The preliminary stage included a presentation to local consultants at Barnet General Hospital and to the LSCH GPs about the programme. The staff had the opportunity to attend a workshop where a short film, *Ex-Memoria* was shown and discussed. The film was from the perspective of a lady with dementia who was a survivor of the Holocaust in Nazi Germany living in a care home. The film and discussion around it gave the staff a 'taster' of the interactive way in which the programme is to be conducted.

Following this preliminary work, a teaching pack and interactive teaching programme was developed to be delivered in 10 monthly sessions. Local consultants from the Department of Old Age Psychiatry and Medicine expressed their support for the project.

The principles and contents of the course are shown in appendix 1.

The training course was organised to help the staff develop reflective and experiential learning to enable them to appreciate that "all people have a unique history and personality, and that this will affect their cognitive disabilities". (Dawn Brooker, *Person Centred Dementia Care: making services better*, 2007). The sessions attempted to promote the concepts of "My Home Life", creating conditions where individual resident's needs and preferences were identified and acknowledged.

The course was also designed to encourage them to reflect on their own interactions and to try and consider issues around end of life from the perspective of the individual living with dementia and their relatives' (Dawn Brooker, 2007).

Each session consisted of a short factual presentation, followed by small group discussions and then further small group discussions on case scenarios illustrating issues around end of life. The sessions, each for 1-½ hours, were held four times in a month; two sessions during the day and two sessions just before the night shift specifically for night staff to attend.

For more details about the programme please see the supplement to this report titled *Improved End of Life Care for people with Advanced Dementia: A reflection of the learning for staff working in a care home setting*, 2012.

TRAINING AND DISCUSSIONS WITH NON-CARE STAFF AND RELATIVES

In addition to the training provided to the care and nursing staff, a short training course was provided to the remaining members of staff, including administrative and housekeeping personnel. They were very enthusiastic and pleased to be included and learn about the principles and practice of end of life care. The examples they brought to the training showed that many staff who were assumed to be "behind the scenes" were in fact building up very close relationships with people who live in the home and their relatives. They were aware of the deterioration of the residents and wanted to know their place in the care provided.

In a meeting with relatives of people with dementia who lived at LSCH at the time, some of the issues of the programme were discussed. Relatives expressed support for the project and were also very appreciative of the opportunity to be told about it and possibly contribute to it. One of the suggestions raised in this meeting, to have a condolences book at the home when a resident dies for staff to be able to write in and later present to the family, was later implemented and found to be very much valued by staff and relatives.

THE REGISTERED MANAGER'S PERSPECTIVE ON THE PROGRAMME

The registered manager joined LSCH when the background of the project had been set up and became involved in the shaping of the intervention and the decision to postpone from the GSF training until the following year.

Plans to recruit a clinical nurse to lead the embedding of learning into practice were unsuccessful until much later in the project (January 2011). In view of this it became important for the work to be carried out by the home's management team. The everyday support for nurses and care staff on each of the floors became the remit of the care managers on each of the floors, under the home's registered manager's guidance. The registered manager took the lead in working with the intervention lead which meant that she was able to form good working relationships quickly with the staff in the home, particularly the night staff. They were surprised and impressed that the manager would work with them on their shift rather than require them to always come during the day. This helped with the culture change required by the intervention.

It became obvious in the early stages of the intervention that day staff found it very difficult to be released to attend the day sessions and if they did, they felt guilty that they were increasing the workload for their colleagues.

Deferring the Gold Standard Framework training, until mid-point of the intervention, meant that the two projects could run in tandem with learning and practice being developed without compromising the research.

CHAPTER 3: EVALUATION

PROCEDURES

Staff - All staff working in the home on a permanent basis in either a nursing or care assistant role, and who had been working directly with residents at the end of their life were eligible. We wrote to them, enclosing an information sheet, saying that the interview was confidential unless residents were being harmed and all data would be anonymised. The research assistant interviewer visited the home during different shifts and care staff were asked if they wished to talk about the study, and if so were seen individually in a private room, at a convenient time. Initial qualitative interviews continued until no new themes arose and theoretical saturation was reached. All staff who were working in the home pre-intervention were approached post-intervention if they were still working in the home and asked if they were willing to be interviewed again.

Family carers - Family carers were sent a standard letter from, or approached in person by the home about the assessment. There were also posters in the lift and the research assistant attended a family carers meeting. If family carers told the home that they agreed to be approached, the researchers sent an information sheet with full study details including possible benefits and risks. Their written informed consent was obtained prior to interview and at least 24 hours after they had received the information sheet. If the family carers agreed to the project, we then approached the person with dementia for whom they cared. Families were asked to consent to the project and to be approached in the event their family member died.

Residents and family carers:

- We completed a short demographic questionnaire– age, sex, ethnicity,
- Quality of life before death– We used a validated quality of life measure (Quality of life-AD; QoL-AD(Logsdon et al., 2002)) which can be used by family and asked family members to fill it in after someone had died to consider the end of their relative's life. Higher values suggest higher quality of life
- We asked family carers to fill in a self-complete questionnaire which is validated throughout the age range– the GHQ (General Health questionnaire)(Goldberg, 1986) Higher values suggest higher stress levels. Values of 5 and above are often used to indicate the point at which intervention is indicated.
- After a resident had died, we asked family members to complete the toolkit After-death bereaved family member interview. Taken from the Toolkit of instruments to measure End of Life care, it explored four domains around the residents end of life care; (1) Physical comfort and emotional support, (2) Promoting shared decision making, (3) Focus on individual patient's expectations and needs, and (4) Attention to the emotional and spiritual needs of the family (Teno et al., 2001).
- We also performed a qualitative after death interview with family carers three months after death and if they were willing. This used open questions with an interview guide
- Care home notes– We read the notes of residents who had died during the year pre and post intervention and extracted the following information: existence of advance care plans including do not resuscitate plans; place of death; match up between plans and interventions and place of death.

STAFF INTERVIEW

We interviewed staff asking them to think about their care of a recent relative they knew who had died. We explored staff's confidence and satisfaction with the process. We asked if they feel allowed to do what is in the best interest of the patient? We enquired whether they could access the help needed? We also asked about their experience of any gaps between the resident's culture and their own and what that meant to them.

Before the intervention, the approach to end of life care in the home was reactive rather than pre-planned and the pre-planning that did occur was not consistently recorded. Care was focused on the presenting condition or

symptom. Behavioural problems were sometimes attributed to dementia rather than physical discomfort or pain. Staff found it really difficult to talk to relatives and few detailed life histories were taken from family members leading to less effective communication between nursing staff, GPs and some families.

Staff many of whom had English as a second or third language, could often appear to be defensive and families often underestimated the affection they had for the residents. Staff felt defensive and frightened that they might be blamed when things went wrong or a person died. Some were of the opinion that the relatives failed to understand dementia and how it affected people.

Before the intervention, there was a belief that hospitals were the appropriate place for people whose health was failing. Some nurses, care home staff, and relatives felt unsupported with the process of dying. The relatives also thought they were ill informed about choices. At times the communication between the GPs and staff in the home was strained due to the lack of clear, shared terminologies. The training and support to care home staff did not fully address the staff's anxiety caring for people with increasingly high or complex care needs including end of life care and the number of people being admitted who were close to death. The floor managers reported that the training they had received was fragmented and did not necessarily follow a logical order.

Job content Questionnaire – this is because the most adverse job-related strain reactions are to be expected in jobs characterised by high job demands, low control and low worksite support. We were in particular concerned with the satisfaction subscale as we wanted to find out whether the intervention affected job satisfaction (Karasek et al., 1998).

ANALYSIS

Our predetermined analytic plan considers data concerning residents with dementia and who had been living in the home for one month or more before they had died so that there had been an opportunity to make plans in the home. Quantitative data was analysed using SPSS to generate descriptive statistics and to compare place of death; documents regarding advance care and whether these were kept to in the year before and after the intervention. We employed chi squared analysis for categorical data, t-tests to compare means for normally distributed data and Mann-Whitney for other data. We also analysed in the subset of people for whom we had data after death relative stress (GHQ) and resident quality of life before death and compared the time periods.

All qualitative interviews were taped and transcribed in full. Thematic analysis supported by the Atlas-ti qualitative data analysis package, was used to identify main themes emerging from the qualitative data collection and the relationships between these themes. The transcripts were read and re-reading transcripts, and two researchers independently coded them to increase validity and a consensus was reached on the coding frame. We aim for maximum variation samples covering all the demographic groups and to interview until no new themes arose (theoretical saturation).

CHAPTER 4: RESULTS AND OUTCOMES

I) DATA FROM RESIDENT FILES

Selection of data Figure 1 shows the selection process for those included in the analysis 112 files of residents who had died in the 12 months prior to (n=68), or 12m post intervention (n=52) were examined. Of these, 98 had been resident in the home for >1m when they died.

Resident Demographics (see Table 1)

Residents who died before and after the intervention were in their mid to late 80s and more were female. Slightly more had a known diagnosis of dementia after the intervention -53% versus 69%.

Place of death (See Table 2)

There was a significant increase in the proportion of residents with dementia dying in the care home (as opposed to hospital) from 14/30 (47%) before the intervention to 22/29 (76%) after intervention; $\chi^2(1) = 5.3, p=0.02$. There was also a significant increase in residents with dementia who died with any advance wishes in their notes: Do Not Resuscitate (DNR) increase from 4/28 (14%) pre-intervention to 16/22 (73%) post intervention, $\chi^2(1) = 17.5, p<0.001$, and a similar finding for those without dementia (n=27), increasing from 2/20 (10% before intervention) to 6/7 (86% post intervention), $\chi^2(1) = 14.3, p<0.001$. There was a non-significant trend towards an increase in other kinds of advanced wishes. Where it was possible to discern from the notes (n=20), the percentage of residents with dementia whose end of life care was in line with their advanced wishes regarding hospitalisation or DNR forms significantly increased from 71% to 100%, $\chi^2(1) = 4.1, p<0.04$. There was a trend towards a decrease in the number of days spent in hospital in the 3m prior to before or after the intervention (8.5 versus 7.6 days).

II) DATA FROM FAMILY CARERS INTERVIEWED AFTER THEIR RELATIVE RESIDING IN THE HOME DIED (see Figure 2 as to who was interviewed and Table 3 and 4 for characteristics of participating residents and relatives.)

53 relatives of residents with dementia in the care home consented to take part in the study. 20/26 (77%) of these relatives who were bereaved during the data collection period agreed to an after death interview. The relatives covered the range of demographics in terms of sex, relationship to the person with dementia, age group and education. They were most often children of the person who had died but also included spouses and other relatives. They covered a wide age range from 20s to 80s and the majority were woman. As would be expected most of the residents who died were in their eighties and had severe dementia.

Quality of Life before death and family carer wellbeing (see table 5)

There was a trend for the proxy QoLAD before death to be higher post-intervention compared to pre-intervention (median 21 versus 18). The family carer reported less symptoms of anxiety and depression after the intervention than before (GHQ median score fell from 3.5 to 1.5). As there were only 12 people in the preintervention and 8 in the post intervention group these results did not reach significance.

After death interview (Table 6)

There were small numbers who filled in this interview. For interest we have added a column considering statistically significant differences in individual questions but do not expect them with such a small sample.

Families saw no change in the general attitude of paid carers and they remained in the main kind and respectful. Changes were in the right direction with families reported being consulted more about decisions and being supported more. The vast majority still felt they did not know what to expect at the end of life, although there was slightly more who felt informed than before. As might be expected with more people dying in the care home than in hospital, there was no improvement (but importantly no deterioration) in pain relief. The rating for overall symptom control which had been high improved slightly. There was little difference in medical care. The most

important question was probably overall satisfaction with care given at end of life on a scale of 1/10 with higher numbers meaning more satisfied. The mean post score increase from 7.5 sd=1.3 to 9.1 sd=2.4 vs mean pre score 7.5,, $t(17.6) = -2.0, p=0.06$.

III) FINDINGS FROM ANALYSIS OF INTERVIEWS WITH RELATIVES ABOUT THE TIME AROUND THE RESIDENT'S DECEASE (see quotes and number of times mentioned in table 7 and 8)

Examination of the coded interview transcripts revealed that some codes only occurred in interviews with relatives before the intervention was implemented in LSCH, and others only occurred in interviews after the intervention was complete. These indicate changes.

Codes which only occurred before the intervention was complete were:

1. Staff not coordinating care at end of life. There were 14 separate comments covering such issues as staff having difficulty in communicating with each other and to relatives about end of life, and this included in discussion of religious wishes and procedures.
2. Support for families being inadequate. Families would have appreciated more support, before, during and after end of life. This might explain why religion was mentioned pre-intervention as being supportive but not after the intervention - or it may be that the 8 people interviewed post intervention were less religious.

These codes do not occur in any interviews following the intervention phase, suggesting that the training may have helped staff communicate better about end of life with family members, and to be better prepared for it, both emotionally and organisationally. The training may also have resulted in families feeling better supported by LSCH both in making EoL decisions and at EoL itself.

Codes which only occurred after the intervention was complete are in the main:

1. around care at the end of life. Relatives are pleased with the care, they understand issues around symptom control, they feel that staff recognise when someone is reaching the end of their life.
2. around decision making - relatives feel supported in making decisions, they understand that planning is needed because age itself won't predict when someone will pass away, and perhaps because the person themselves can't make decisions, some people do not feel that planning is necessary, either because they don't want to make those kinds of decisions themselves or because they feel LSCH will guide them sufficiently.

There is still room for improvement. It appears that communication about deaths that take place when family members are not there is sub-optimal, and that GPs at the home might benefit from similar training to staff, as they are mentioned as being less clear in their communication.

In general the themes arising in interviews after the intervention are more disparate and there are less comments. No new themes arose after only eight interviews, which means the likelihood of some representing unique sets of circumstances is increased.

STAFF OUTCOMES

Staff felt better equipped to deal with the frailty of the nursing home residents.

Staff felt more skilled in talking face to face with relatives and GPs about distress and pain as well as death and dying.

Staff feel more confident and comfortable with end of life planning and communication following training.

Staff feel less worried about blame because they feel confident that they follow advanced wishes and feel they do

their job well.

Staff are more aware of the Gold Standard Framework and coding of residents condition.

Staff feel the training has been helpful and they have a greater understanding of end of life care and advanced wishes.

Staff feel training has improved things in the care home.

Staff have a greater understanding of the importance of having advanced wishes in place.

THE CARE HOME

Following the intervention, there was a change in culture as the staff got to know each other better and the staff team was strengthened by regular supportive reflective sessions.

MANAGERS' PERSPECTIVE OF IMPACT.

The current home's manager joined the home when the planning for the project had started in April 2009. She had been a GSF coordinator in her previous residential home where she had been involved in end of life care. She recognised in March 2009, that the home needed to postpone its introduction to GSF work as it would not fit into the time frame of the project. She also felt that she needed to change the culture of the practice on the three floors. They each had different managers and different ways of working and she needed to create more of a sense of a whole in order to make reality of the wish of one home. Now whereas each floor has individual ways of working, it feels one home in terms of agreed processes; systems; training and supervision. The project was part of the process that led to this, alongside some changes in management of the floor and recruiting a deputy manager.

At the beginning of the project, the home had a holistic therapist who had previously won a prize for palliative care, who worked over 4 days to support people at the end of life and had experience of particularly helping those with advanced dementia who no longer had verbal skills. Whereas she helped on session 8, she was ill for some of the time during the project and her input during the intervention whilst valuable has had little impact on the practice. She is available for some of the residents who value her services but she has reduced her time in the home to two days a week where she works mostly on the 1st and 2nd floor and has been teaching staff hand massage to support the clients who like this practice.

The managers of each floor were supportive of the project and the need to change culture but each of them had different issues to resolve given the different staff and residents they catered for. The First floor staff look after people with the most challenging behaviour they all are diagnosed with dementia, but not all at the end stage, some of the residents living on the floor for more than 5 years. On the second and third floors, not all the people had dementia and those that did were at various stages and had various other health issues. Traditionally the more physical nursing care was delivered on the second floor but gradually, because of the interest of the 3rd floor manager in end of life care, more people with this need who may have had dementia were cared for on her floor.

There was variable work with the GPs and there have been changes to GPs during the project. They were open to the project especially in terms of consistency of paperwork across the home and policies that each floor would follow in a standardised way. However, they found it also challenging that people with increasingly complex health needs were being admitted to the home, often with minimal paperwork and information prior to admission.

For the staff, the increased frailty in clients left them feeling ill-equipped to deliver the care to the level they would wish. Speaking to the staff before the intervention we found that people while good at providing the face to face care, were reluctant to discuss it and felt uncomfortable around some relatives.

The manager felt that the intervention would work better, if she worked with the floor managers directly, and their staff attended the sessions. The managers would then pick up and develop the learning between sessions at

reflective and handover sessions, particularly in relation to the new tools that were introduced towards the later sessions and on how to hold end of life discussions.

By November 2009 the manager attended with the floor managers, the GSF training so that the home could be accredited. Because of changes to management over the period, only the 1st and 3rd floor managers (one who was to become the deputy) and the home manager were consistent in attendance and then as they were recruited the different 2nd floor managers also attended as well as the new 3rd floor manager. Only new managers were recruited if they had GSF or other end of life care knowledge. In addition the original 3rd floor manager embarked on courses in end of life care and the Foundation course in palliative care at the North London hospices with two of her nurses. The Foundation course was considered valuable and by June 2011, the new 3rd floor manager and 5 nurses from all the floors were on the course, together with one of the social workers from the organisation. This learning together at the hospice will hope to strengthen the partnership work between home, hospice and social work team in Jewish Care.

The manager found that the intervention strengthened the staff team and the regular monthly sessions were a good way of getting to know them for herself and each other, particularly the night team. From the beginning, the night staff as a whole group, showed commitment. The manager was amazed at the number of night staff turning up without fail to the sessions. They always came in early; were ready to participate and were open to changing practice and in addition they debated the various issues openly citing different issues often from up to 20 years previously. It felt to the manager, that they were untapped resource within the home. It allowed them to become more valued members of team as they discussed issues across the floors and looked at ways of working that would support across the home to improve care for the residents.

The 1 ½ hour sessions worked well for the night staff but were problematic for the day staff who felt guilty leaving their colleagues on the floor and often, it was not practical for the managers to release the staff because of the frailty of the people being cared for. Later in the intervention, catch up whole day sessions took place which were much more successful in engaging the day staff and this method of training will continue in the home.

With the difficulty of recruiting a clinical nurse specialist, the homes manager and the organisation looked at the job description and felt that they would improve their chances of recruiting if they widened the role and included the new post of deputy to the home. Meanwhile the manager of the 3rd floor continued to develop her interest in end of life care and in the summer of 2010 applied for the new post of Deputy to the home which included improving nurse practice and being an end of life clinical nurse specialist. Having been appointed, it took until January 2011 to release her as she needed a replacement as manager of the 3rd floor.

The relatives during the time of the project were not a static group. It was often difficult for the researchers to meet with them. Anecdotally, some of them spoke of how supportive other relatives were and the coffee shop offered a venue for that support. At the start of the projects we had a complaint about refreshments at night when the coffee shop closed and since the project has started, the complaints that have been received have been about the timeliness of death certificates for speedy burial and only compliments have been received about the quality of end of life care.

The manager introduced the project to the volunteers. Only the religious service volunteers showed any interest as they would occasionally support a resident they knew at the end of their life. A volunteer came forward who was experienced in palliative care to set up a befriending project but it was difficult to release the deputy so she could help her set up the project. However, very few residents seemed to want to speak to anyone they did not know about end of life, they were offered but refused the opportunity to speak to a rabbi. Only one person wanted to speak to his or her own rabbi.

The home introduced a Condolence book at the beginning of January 2011. The idea had come from a number of sources. It was mainly the relatives who wanted to know who had passed away and share messages with other relatives. The volunteers did not engage with this either. The manager drove it, but from the beginning relatives and staff wrote messages, but only particularly for those residents who take part in the social life of the floor and home. The manager hopes that this project will be further delegated to staff.

The two largest changes in practice was the introduction of Advance Care Wishes and improved pain relief.

In terms of advance care wishes, the only information that was received from a person or their relative was about whom to contact in an emergency and where the person was going to be buried and this was not always documented. The forms for the advance care wishes were completed during the training intervention; then interested staff were trained to carry out the conversations. The floor managers took on the project and with the home's manager started the conversations and whilst many relatives were ready to talk they were often difficult conversations. Sometimes there was a mixed reception to the topic which some not wishing to talk but knowing that it was a possibility if they wished. The manager on the 3rd floor had one relative who was offered the opportunity to speak over some months, and then a week before his mother's death, he felt ready to speak to the manager. As part of his discussions took place with families and the GP regarding whether the person wanted to go to hospital at the end of their life; whether if they died suddenly they wished to be resuscitated. All this was explained to people and within a few months, most residents had documented in their care plans their wishes. With the discussion on resuscitation, came the DNAR forms for those who knew their relatives would not have wanted resuscitation, as well staff on each floor trained in CPR and staff aware of who wants resuscitation and who doesn't.

In addition, at the relatives meeting in August 2010, the project was discussed and ideas about a leaflet sought. The leaflet went through several changes and was ready for publication in Spring 2011.

Staff were more likely to ask residents than relatives for their wishes. They also took on using the Abbey pain scale, particularly on the first floor. They used the pain scale as a base line on admission then checked regularly. Evidence for use of medication changes, particularly use of pain relief and anticipatory prescribing for pain relief was documented more clearly, especially over a weekend.

It is clear that the long standing members of staff benefited from some of the repetition of the topics as well as the style of the training sessions; the discussions and debates in the workshops with the old age physician. The staff were fully involved in debating which pain scales to use, the changes of paperwork which they helped design and in changes to other systems. In addition, the high percentage of staff attending sessions on a monthly basis led to a consensus on ways of working and it included the night staff. It was clear as new staff came to the catch up days that the whole team embraced the new culture, as when they attended they already had some knowledge gained from working in the home which they accept as the established norm. The "surprise" question, the 4 different stages identified in the GSF had become very much part of the care in the home. And the training sessions for domestics and support staff which were well received show how much the acceptance of talking about living well to the end was part of the culture.

CHAPTER 5: LEARNING FROM THE PROJECT

THE RESEARCH:

Those working in the home were pleased that the researchers on the project (both Catherine and Elle), spent time getting to know the home, the staff and the residents and their families. Catherine had previous experience of working as a carer and understood shift patterns and how a home worked and how busy it can be. Both researchers supported the view that the home was not a laboratory for research, but a busy, complex environment with changing clientele. At first staff did not come forward to engage in the research, part of this was to do with the floor managers who were positive about the research but did not ensure that the time and space were made available because of the competing needs of the work. Catherine was very helpful by being incredibly flexible even to the point of coming in the middle of the night to carry the one to one meetings required to suit the staff on duty.

Once people started having the 1:1 meetings, word of mouth was that it wasn't scary, arduous or frightening, so more people agreed to participate. Catherine left the project at the end of the pre-interviews and Eleanor had to fit into the existing project and get to know the home, the way it worked and the staff very quickly. However, the after interviews were much easier because Elle only wanted to see people who had previously met with Catherine and it was easier to arrange interviews around their shift patterns and the home managers had become much more familiar with the needs of the researcher.

Whilst the home did not know what individuals had said, it became obvious from handovers and conversations that staff were starting to open up about death and dying from participating in the 1:1 pre intervention interviews.

Another part of the research was to look at the care plans and notes. It became apparent that very little was consistently documented about any end of life wishes other than burial arrangements which in the Jewish religion is very important to record as funerals take place very quickly after death. Synagogue membership means that funerals take place without separate arrangements taking place beyond informing the rabbi. This informed the intervention which spent much time looking at communication and Advanced Care Wishes.

INTERVENTION:

Planning the intervention was not straightforward as although the aims were clear, how much knowledge the staff had was not known. It was decided to show the film *Ex Memoria* as it had been filmed in a Jewish home and focused on a woman who had experienced the Holocaust in occupied Nazi Europe. The film confused staff because it was not on end of life per se and did not obviously jump into the topic of death. It provoked discussion, which was the point of the exercise. The manager saw the differences in staff's perception of the film from their own culture backgrounds and knowledge of Jewish history. It certainly met its aims for the participants of

- To learn how to observe from different points of view
- To find out staff's views and concerns.
- To encourage staff from different viewpoints to work together.

Staff were interested in attending and because it felt the start of something new. It was however, a struggle to get all participants to join in and debate issues and groups tended to be dominated by a few strong individuals. This led us to plan the intervention as interactive, with staff working in small groups, using case studies as scenarios as the basis of learning. The case studies chosen were those that addressed the particular concerns of the staff.

This pre-intervention informed the programme for the 10 session intervention. It was important that all the staff had opportunities to attend as many sessions as possible so it was planned that there would be 4 sessions on each topic spread over a month in order to provide training on a day when each of the 4 staff team were working. Each session was for an 1 ½ hours, two between 2.30 and 4pm and two between 6.30 and 8pm. Over time, the daytime sessions were less well attended as day staff struggled to leave their floors and if they did attend, felt guilty leaving

their colleagues which affected their participation in the sessions. However the night staff came out in force before their shift and they felt valued by the training as they had never had such an intensive input into their training at a time that suited them. Nevertheless, they were not good at diarising when the sessions were, so it became apparent that the training needed to be on the second day of a shift so that they could be reminded of the training. When a reminder wasn't given, many failed to appear.

Whilst, the individual sessions were mainly positive, there were times that the trainers felt that the participants had still not taken away the really key points that were being discussed. Also, some staff felt that the case studies presented were very repetitive, although for others this gave them several opportunities to learn and consider changing their practice and reinforce the message.

By the end of the intervention, some day staff told us that they would have liked to have attended but found the timings awkward and would have preferred a whole day. Thus, after the 10 session intervention ended, we planned the full day sessions. There have been 4 whole day sessions since, attended by a mixture of newly recruited staff and those staff who either didn't attend or attended 4 or fewer of the sessions of the intervention. These whole day sessions were very well attended and received very positive feedback. We noticed that in these sessions that everyone was far in advance of the knowledge, skills and attitudes of staff that attended the beginning of the intervention and that was because even though they had not attended the original training, the culture was sufficiently embedded in the workplace to have become part of their practice.

It was realised by the end of the intervention, that there were other staff in the home who perhaps, not providing hands-on care, would still need to understand the principles of the changes of good end of life care and their role in delivering this. Thus a short session, for 1 ½ hours was held for administrative staff; domestics; and laundry staff.

Separate discussions were also held with the kitchen staff and other employees in the home.

CULTURE:

It is difficult to identify the exact moment when the culture changed, as this was a process that evolved over the time. It was helped by introducing the advanced wishes paperwork, DNAR and becoming involved in the GSF, particularly with its language.

Discussions became more common both within the staff team at LSCH and also involving GPs to reflect as well as prepare on end of life care. This has led staff to be more confident about managing acute episodes, which did not require hospitalisation and to deal with the deterioration of people for whom their planned place of death is LSCH. Prior to the intervention, nurses felt isolated in making decisions about hospital admissions and would err on the side of caution; whereas now they know they are part of a team. This is also enhanced by better communication with relatives as well as shared documentation.

Discussions with relatives remain challenging. Managers or senior nurses in their absence are responsible for "Difficult conversations" with families. Care Staff now have a greater understanding of end of life care but still prefer senior staff speak to the relatives in the first instance.

Introducing the GSF gave the staff a language to use when talking about planning end of life care. The A, B, C, D categories and the "surprise" question were seen as particularly useful. The links with the local hospice have also been strengthened through this process.

Changes within Jewish Care's social work team, have meant that there are closer links between the home and the palliative care support team, which has led to regular meetings where information is shared so that families and residents can be appropriately supported.

Despite the improvements generated by the intervention and teaching programme the only significant part of the culture that has changed has been the discussion about death. There is still a lot of work to be done particularly as the teaching intervention was stopped after a year.

WHAT WE COULD HAVE DONE DIFFERENTLY

- Day long sessions were popular with day staff,
- The early evening short sessions worked well for night staff
- The short sessions worked in making sure the topic was on the agenda on a regular basis in the home.
- The failure to employ a clinical nurse specialist post. A dream job description was created and it was found impossible to fill.
- The managers were able to 'own' the intervention in a way not envisaged prior to the project.
- There were problems engaging with one floor, as there were several changes of managers,
- It would have been preferable to have a dedicated nurse, on this floor, to lead through all these changes.
- Better involvement with relatives at their meetings
- Enhanced post death reflective sessions
- To nurture and to train staff in communication and listening skills
- More involvement of GPs
- Better sharing of Jewish Care policies with visiting GPs.

WHAT WORKED?

- A manager was at almost every session showing commitment to the intervention, its message and ensuring consistency
- Training almost all the staff meant that the whole home was committed to change
- Case studies and small groups enabled staff to be open to new ideas and gave those with less confidence the opportunity to talk
- Unit managers and their reflective sessions on the floor
- The introduction of new paperwork and the discussions that took place in their development
- Pain scales to support staff working with people with dementia

APPENDIX 1:

The programme was designed to help staff understand the following themes:

- dementia as a terminal condition
- end of life in advanced dementia
- respect for the individual and their family using relationship centred care
- dignity and humanity
- No secrets
- the skills and competencies and communication required.
- physical and medical issues around end of life
- The effect of different interventions at the end of life
- the principles of palliative care and pain management, particularly using pain scales.
- the rights and needs of older people and their families at this time
- Advanced care planning and advanced wishes
- The Jewish perspective of end of life, death and dying
- their own personal attitudes to death and dying and end of life care
- How to use the forms enabling the staff to work with families and residents, where possible, to document their advanced wishes
- Documentation of cardio-pulmonary resuscitation status
- The use of the Gold Standard Framework offering a systematic approach to providing dignified care at the end of life.
- Maslow's hierarchy of needs
- some of the behavioural and psychological aspects of dementia
- The principles of comfort care especially during the last few days and hours of life.
- Nutrition and malnutrition in end of life
- Bowel and bladder care at the end of life
- Pressure sore prevention
- Mouth care
- the issues around swallowing and aspiration at the end of life in advanced dementia
- the relevance of the Mental Capacity Act when planning end of life care.

- To help people be less worried about the dying process.
- To have a better understanding of loss and bereavement.
- To understand Advanced wishes, Advanced planning and the difference from care planning. The goals and objectives of the course were to encourage participants:
- To feel involved,
- To reflect on their own interaction with residents and relatives
- To develop their listening skills
- To challenge their own practice.

FIGURE 1. FLOWCHART SHOWING SELECTION OF RESIDENT RECORDS FOR ANALYSIS

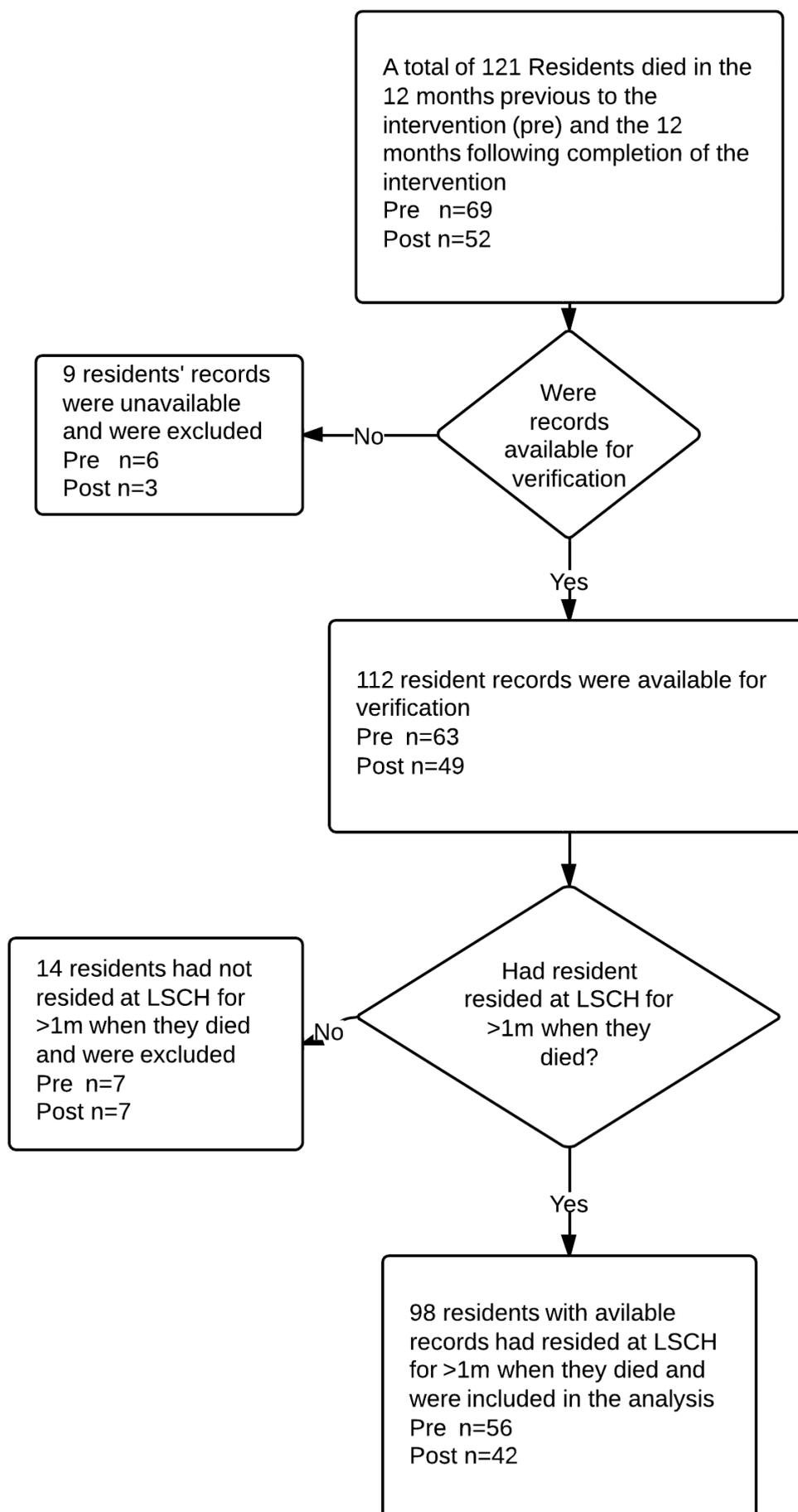


TABLE 1. DEMOGRAPHIC INFORMATION OF RESIDENTS PASSING AWAY AT CARE HOME BEFORE AND AFTER INTERVENTION

Characteristics	Died Pre-intervention (n=56)	Died Post intervention (n=42)	Data missing (n)
Mean age at death (sd, range)	85.5 (7.9, 63-104)	88.1 (7.1, 73-102)	0
Female n (%)	61 (34)	25(60)	0
Dementia diagnosis n (%)	30 (53)	29 (69)	7 (7.1)

TABLE 2. OUTCOMES AT TIME OF DEATH FOR RESIDENTS WITH KNOWN OR SUSPECTED DEMENTIA RESIDENT IN THE CARE HOME BEFORE AND AFTER INTERVENTION

Measure	Pre-intervention	Post intervention	χ^2 (df)	p
Number and % of residents with dementia dying in care home (vs hospital)	14/30;47%	22/29; 76%	5.3 (1)	0.02*
Residents with a Do Not Resuscitate order (DNR) in place	13% (4/28)	73% (16/22)	17.4 (1)	<0.001*
Residents with advanced wishes other than DNR in place	11/28;39%	15/23; 65%	3.4 (1)	0.06
Residents whose DNR or hospitalisation was in line with their advanced wishes	5/7; 71%	13/13; 100%	4.1 (1)	0.04*
Days spent in hospital in 3m prior to decease (median; range; inter-quartile range)	4 (0-34;15.75)	1.25 (0-68; 9.5)		

FIGURE 2. FLOWCHART OF PARTICIPANTS IN THE STUDY

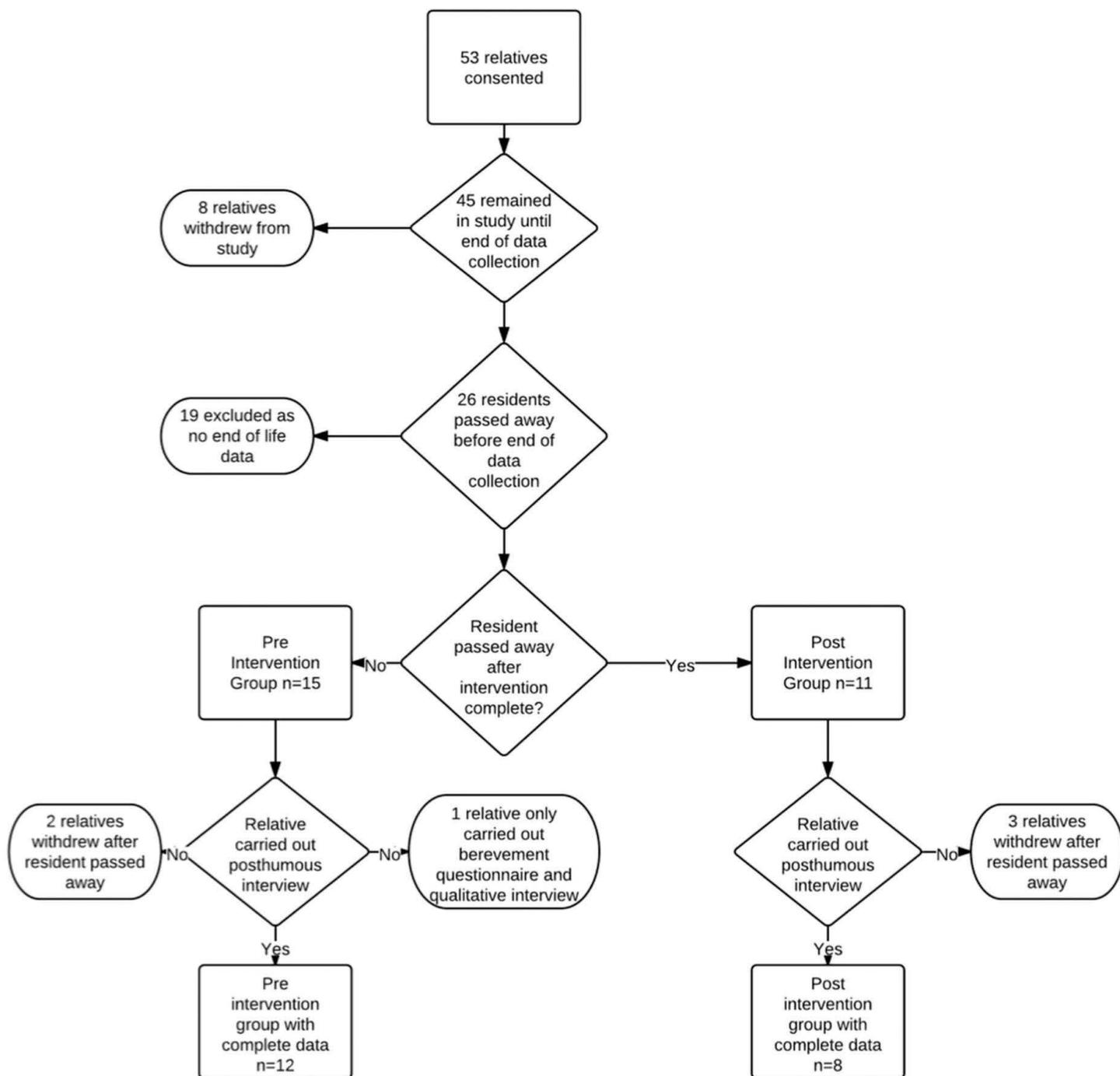


TABLE 3. THE DEMOGRAPHICS OF RESIDENTS WHOSE RELATIVES WERE INTERVIEWED AFTER THE RESIDENTS DEATH)

Characteristics	Died Pre-intervention N=12	Died Post interventionN =8	Data missing (n)
Mean age (sd, range)	87.7 (12.3, 60-100)	87.6 (5.6, 81-95)	4
Female n (%)	9 (75)	3 (38)	-
MMSE score (sd, range)	5.3 (6.7, 0-28)	7.8 (9.7, 0-22)	3
Education beyond school n (%)	1 (8)	0 (0)	3
Marital Status at recruitment n (%)			1

TABLE 4. DEMOGRAPHICS OF RELATIVES INTERVIEWED AFTER DEATH (N=20)

Characteristics	Pre-intervention (n=12)	Post intervention (n=8)
Mean age (sd, range)	55.9 (11.7, 33-68)	62.9 (19.8, 22-85)
Female n (%)	8 (67)	4 (50)
Education beyond school n (%)	8 (67)	3 (38)
Marital Status pre- bereavement (%)	Single 2 (17) Married 8 (67) Divorced 2 (17)	Single 2 (25) Married 6 (75) Divorced 0 (0)
Relationship to resident	Child 7 (64) Spouse 1 (8) In-law child 2 (17) Other 2 (17)	Child 4 (36) Spouse 3 (38) In-law child 0 (0) Other 1 (13)

TABLE 5. QoL-AD PROXY FOR LAST DAY'S OF RESIDENT'S LIFE AND RELATIVE'S GENERAL HEALTH QUESTIONNAIRE SCORES IN PRE AND POST INTERVENTION GROUPS AT AFTER DEATH INTERVIEWS

	Group	N	Median	Inter Quartile Range	Mann Whitney U	p value
QoLAD proxy last days of life	pre	12	18	7.3		
	post	8	21	4.5	U(20)=27	0.102
GHQ-28 relative after death interview	pre	12	3.5	15		
	post	8	1.5	2.5	U(20)=40.5	0.579

TABLE 6. AFTER DEATH BEREAVEMENT QUESTIONNAIRE COMPARISON OF PRE AND POST INTERVENTION ANSWERS

Question	Number Pre/post intervention	Yes%	No%	χ^2	P
Care Decision Made With Enough Family Input?	13-Jul	69/100	31/0	2.7	0.1
Information About What to Expect at EoL Given?	13-Aug	23/38	77/82	0.51	0.48
Right Amount Pain medication?	06-Jun	83/83	17/17	0	1
Know Enough About Medical History?	13-Jul	92/86	Aug-14	0.22	0.64
Enough Help Available for Personal Care Needs?	13-Aug	85/75	15/25	0.3	0.59
	Number	% Always	% Usually	Chi squared	P
How Often Personal Care Optimal?	12-Aug	66/50	17/50	3.3	0.19
How Often Resident Treated with Respect?	12-Aug	75/75	25/25	0	1
How Often Resident Treated with Kindness?	12-Aug	75/75	25/25	0	1
	N	Score (1-10)	SD	statistic	p value
How Well Did Staff Communicate?	13-Aug	6.7/7.1	3.1/2		
How Well did medical care respect resident's wishes?	12-Aug	7.8/7.8	2.8/1.6		
- Acceptability of symptom control?	11/8	7.4/8	3.3/2		-
How Well Did Staff ensure resident died With Dignity?	13-Aug	8.5/9	2.1/0.75		
How Well Was Emotional Support Provided For Family?	13-Jul	6.2/7.3	2.8/3.1		

TABLE 7 CODES WHICH ONLY OCCUR IN INTERVIEWS BEFORE THE INTERVENTION TOOK PLACE

Code name	Example Quote	Number of times coded	Interpretation of code
Lack of coordination around End of Life Care	“035: ...so they were very good..., but then, as the evening wore on ...she passed away around 8 o'clock, which must have been just at shift change, cos they all left..., at...sort of around, quarter to...8...we were just sat in there on our own...and...we didn't know really what to do at that point...”	14	Staff did not know how to cope at end of life
Relatives feel staff panic or are not prepared around EoL	“011: And another incident of a carer...sorry, . my mother was dying, but she thought she was going to go like ...very imminently...: and it was sort of a bit of a panic...: ..and in fact then the nurse came in and said no that's not the case they don't think, you know, just things that shouldn't have happened. She was saying things to me that she shouldn't have said.”	14	Staff did not know how to cope at end of life
Relatives are not offered any further support from the home/outside agencies	“035: Well there wasn't any really from...from within the care home I don't think there was any... .. no. I'm not even sure....I guess they were aware, but...but they never actually said anything...., so there was nothing coming from them “	12	Not enough support from home
Some staff viewed negatively by relatives	“039: They were very, very caring and very helpful , except for perhaps the one...the one nurse that sent her into the hospital, , I don't know if it was her poor use of English or her manner, I just didn't get on with her particularly well “	11	Staff / relative communication issues
Staff communication re EoL inadequate	002: [my] sister went to [staff nurse] and said...you know...‘what can we do?’. And she sort of shrugged her shoulders ‘there's nothing to be done’.: But that's not....we weren't satisfied with that	8	Staff did not know how to cope at end of life

Relatives find language around dying difficult	024: We'd get him to a point where he is comfortable and then get him back to the home where he can just sort of ...[short pause]...do whatever	7	Relatives not coping with end of life
Doubt from relatives as to whether staff are expecting residents death	024 Erm. I think it was very difficult to understand whether the home knew...how bad things were	6	Staff not coping with end of life
No conversation or communication around religious wishes and/or procedures at EoL	"001: No no-one, no not in the past week, no [talk about the Jewish way of doing things when someone had passed away]"	4	Staff not coping with end of life
Relatives find support in the structure of Jewish religion around End of Life a support	"026:...you know the cultural structure that surrounds the whole process...: It...holds you: You know ...quite tightly so you're going through that grieving process, but almost with a safety net"	4	Using other means of support
Relatives advance wishes not being adhered to	"039: .I had made it clear that I wanted her to stay here.[in the home] Because I had had the same problem previously ... So I was very clear,...but she just panicked"	3	Staff not coping with end of life
Family did not feel supported in End of Life decision making	024...probably would have appreciated a little more guidance from them. Seeing as they're there 24 hours a day and we couldn't be So there wasn't a huge amount of support I would say.	3	Not enough support from home

TABLE 8 CODES WHICH ONLY OCCUR IN INTERVIEWS BEFORE THE INTERVENTION TOOK PLACE

	Code	Example Quote	no of times coded	Overall interpretation of code
1	Relatives pleased with the care given by staff	36: We-no I think he was well... you know he was treated like all the others. With compassion and care and love...: And-and a joke.	12	Good care at EoL
2	Relatives aware of issues surrounding symptom control	Po 45 -I would've liked something b-more to be done about it but seeing as though it was mentioned so many times one -assumes that they-they-they're couldn't do anything more for her-: without knocking her out.	9	Relative good understanding of EoL issues
3	Relatives felt supported in EoL Decision making	"PO52 so we were in a realistic, understood what was happening, what was going to happen and the options... so there was such support that... and they were...they approached it in a quite caring manner..."	7	Relatives supported
4	Limitations of being prepared by age alone - not a good predictor of death	034: So ...at any time I might have a phone call...and I've always known there is going to be a phone call for the last fifty years... ..I've been her next of kin ... and looking out for her all that time.	3	Relative good understanding of EoL issues

5	Communication about death circumstances vague	034: So...yeah...right. Now I don't know because I didn't go into a thorough investigation into if my mother was in the lounge in the morning or whether it was when she first got up... ..or whether it was at the breakfast table. But she must have come over very poorly.	3	End of Life circumstances not well communicated
6	Indirect communication by Dr	So she [Dr] rang me up and said that my mother was ill...that her oxygen wasn't good...her levels...What did I want her to do. Now was that code for saying she's really very far gone...: ...do we want her just to be put to bed and looked after here...or was it code for saying get to the hospital quickly: What did I...but she was not...didn't tell me...I had to do a guessing game there.	3	Dr perhaps could benefit from EoL training
7	Understand Staff were not direct because trying to be sensitive	036: I did ask her if—if it was coming to the end and she said 'not yet'. We knew it-I think she was under the impression that it wouldn't be long.: and she said 'not yet'....and I knew from her attitude that she had the best thoughts and intentions for [name]-: -and I was happy with that...	2	Relatives good understanding of EoL issues
8	Relatives feel written EoL plans unnecessary because communication fro LSCH so good	49-it [Advance Wishes] didn't have to be written down-because every time he was sick-and needed to go to hospital, it wasn't necessarily discussed but it was a "we think he needs to" And then it wasn't actioned until it-they'd spoken to us.	2	Good care at EoL

9	DNR decision made by Dr	I think the doctor had perhaps said do not resuscitate if-if it had come to that-	2	Dr perhaps could benefit from EoL training
10	Relatives did not see need for End of Life Planning	“034: so...that last wishes meeting...I mean it was discussed... ..I mean they had asked before I don't even know why we had to have that meeting...I had already told...and the Doctor knew already... ..if mummy gets ill you send her to the hospital, it's quite clear..”	2	Not all families want EoL planning
11	Staff recognise end of life signs	045:-well I'm pleased that they recognised that from- it was something quite serious-		Good care at EoL
12	Residents wishes supported by family	045: -it's my decision to make...well my mum's decision to make-...and me to implement it:- -for her.		Relative good understanding of EoL issues
13	Relatives aware of Good Symptom control at EoL	“052..you could tell he was in pain ...but they controlled that, presumably to a level which was ...which he was as comfortable as could be :by whatever painkillers they were then giving”		Good care at EoL

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