Living well in care homes: A systematic review of qualitative studies

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Abstract

Background: Research in care home settings is often negatively focused, portraying life as sterile and devoid of meaningful experiences. Care homes have the potential to influence people’s lives socially, physically and psychologically. It is important to understand what factors contribute to this.

Objective: To conduct a systematic qualitative review of care home life and provide practical recommendations to enhance residents’ quality of life.

Methods: The following databases were searched: PsycINFO, Medline, Web of Science, EMBASE, Allied and Complementary Medicine Database and Cumulative Index to Nursing and Allied Health Literature. References from appropriate journals and individual articles were checked. Papers that fitted our selection criteria were selected. Two independent reviewers assessed methodological study quality. Thematic analysis and meta-ethnographic methods were adapted to synthesize findings.

Results: Thirty-one studies were identified. People in care homes voiced concerns about lack of autonomy and difficulty in forming appropriate relationships with others. Four key themes were identified: 1) Acceptance and adaptation, 2) Connectedness with others, 3) A homelike environment, 4) Caring practices.

Conclusion: Positive experiences in care homes can occur and are important for residents' quality of life. The review supports literature highlighting the need for relationship-centred approaches to care and emphasise the importance of understanding the resident’s attitude towards living in care homes.

 Background

People of all ages live in care homes [1], although most research has focused on older people [2]. Moving into a care home involves life changes that significantly impacts on an individual’s quality of life [QoL]. These include substantial alterations in social interactions and adapting to issues involving privacy, dignity, and independence [2].

Residents are often marginalized and excluded from research [3]. Negative aspects of care home life are often highlighted, e.g. some would rather die than move to a care home [4]. Lack of privacy and dignity [5], regimented routines, and a feeling of emptiness can affect a person’s sense of control [6]. However, some positive aspects, such as improved self worth [7], morale [**7**], and physical functioning [8] have been reported.

With the rising cost of care homes and financial implications for both society and the individual, we need to synthesise residents’ views on what influences QoL, so that care homes can deliver high quality care and minimise distress. Whilst a vast amount of quantitative data is available the validity of using subjective QoL outcomes measures, especially for older people, has been questioned [9]. Previous qualitative research synthesised older residents’ views on QoL in care homes [10], but did not use systematic methods in relation to synthesis or study quality. To our knowledge there has been no systematic attempt to collate the views of different types of people living in care homes, including younger adults, those with dementia and disabilities.

 Our aim is to produce a systematic review of qualitative studies that have examined residents’ views of QoL. Specifically, it aims to identify and summarise the factors that positively influence care home life, and provide an evidence base of practical recommendations to improve QoL.

Method

Inclusion Criteria

* English language studies of mixed methodology but including qualitative research methods as described below.
* The views of residents in a care home. Care home refers to nursing and residential homes. Accommodation described as community villages, supported living or respite stays were excluded.
* Studies had to examine factors that contribute to care home life.

Qualitative research is broadly defined as ‘any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" [12, pg.17]. We excluded studies of personal narratives and stories that lacked data analysis, as some classify them as ‘no finding reports’ [13-14].

Search Strategy

The following bibliographic databases were searched: PsycINFO (1887-April 2009), Medline (1966-April 2009), Web of Science (1982-March 2010), EMBASE (1980-March 2010), Allied and Complementary Medicine Database (1985- Jan 2011) and Cumulative Index to Nursing and Allied Health Literature (l982- March 2010). As there are no gold standard methodological filters in Medline for ‘qualitative research’, consultation was sought from key literature [15]. We used medical subject headings (MESH) and freetext searches related to care/ nursing homes and QoL. MESH terms were exploded and combined. Proven search strategies for PsycINFO for finding qualitative research were used [16].Please see Appendix 1 in the supplementary data on the journal website (<http://www.ageing.oxfordjournals.org/>) for other search strategies.
References from all appropriate journals and individual articles were also checked and relevant articles were retrieved. Figure 1 shows the flow of study retrieval.

Data Extraction and Quality Assessment

Papers were screened for relevance from the title and abstract. Participant details, recruitment methods, qualitative methods, setting and study data (i.e. participant quotes and author summaries) were extracted. Where there were insufficient details in the abstract, full papers were retrieved. For study quality, papers received a score out of 7 for its methodological rigour by establishing the inclusion of;

* An explicit framework and/or literature review.
* Clear aims and objectives.
* Description of context so the reader could relate the findings to other settings.
* Clear description of sample with basic descriptive data,
* Clear description of data analysis methods taking into account audit trails, searching for disconfirming cases, and identification of themes.
* Reliability and validity taking into account confidentiality, consent procedures, credibility checks and data triangulation methods.
* Sufficient original data to mediate between evidence and interpretation to allow the appraisal of the fit between the data and authors’ understanding [17, 18, 19, 20]. We did not exclude any qualitative studies as poor reporting of methods does not necessarily imply poorly conducted research [21]. All papers were assessed independently for quality and disagreements resolved by the research team.

Data Synthesis

For the data synthesis we followed a thematic analysis approach [22] with a number of features adopted from literature on meta-ethnography [23]. The act of synthesising and reviewing qualitative research are still unclear. However, by using the earliest published work on qualitative synthesis [23], we utilised an established research method of systematic comparison of studies [23] and employed 'thematic analysis' in order to formalise the identification and development of themes [22].

First, each study was repeatedly read and findings highlighted on a line by line coding of data. Please see Appendix 2 in the supplementary data on the journal website (<http://www.ageing.oxfordjournals.org/>) for more details.

Codes were organised in Microsoft Excel, allowing similarities and differences between studies to be identified easily. Towards the end of analysis, diagrams identified links and inter-relationships among categories, to develop themes and subthemes. The final step went beyond the content of the data and themes identified, analysing data in a way that offered an, ‘interpretive explanation through which the meanings of social phenomena are revealed’ [23]. This stage is the most difficult to describe, since it is dependent on the insights of the reviewers, and the inference of additional concepts, understandings or hypotheses as generated from the data.

Results

Literature search and study descriptions

We identified 1048 papers, and 31 papers [24-54] fulfilled the inclusion criteria (see diagram 1). The synthesis of findings involved 1223 participants aged from 20 to 100 (see table 1). There were 29 studies of older residents, 1 with people with Multiple Sclerosis [49] and 1 did not offer any age-related information [35]. Four homes specifically stated that people with dementia resided in the homes [31, 34, 41, 42]; one study was multisited and included homes specializing in Alzheimer’s [25]. Nine [26-27, 33, 37-39, 43, 49-50] included residents with mixed cognitive and physical abilities, and 17 [24, 28- 30, 32, 35-36, 40, 44-48, 51- 54] did not report the residents’ cognitive or physical abilities. Ethnicity was reported by 12 and 27 used in-depth/ semi-structured interviews. Studies covered a range of epistemological perspectives (grounded theory, content analysis, thematic analysis etc). This methodology fulfils the goal of qualitative synthesis: ‘to produce a new and integrative interpretation of findings that is more substantive than those resulting from individual investigations’ [55].

In terms of study quality, only 8 [25, 27, 29, 33, 44, 49, 52-53] met all 7 quality criteria and 17 [24-27, 29-33, 36, 38, 40, 44, 49, 51-53] met both criteria evaluating reliability and validity. Sensitivity analyses (calculating the contribution of each study to the four themes) according to the quality rating score, showed all findings contributed to key themes irrespective of score (contact author for further details). In terms of generalisability, studies from two countries had poor quality scores [28, 34].

Key themes

Acceptance and Adaptation to their living situation

Acceptance of one’s living situation resulted in a more positive outlook (see table 3 for resident quotes and table 4 for themes) [25, 27, 30-33, 35, 37, 41, 44, 46-49, 51, 53-54]. A positive attitude was found to reduce the impact of losses, e.g. with dependency [27, 35, 41-42, 46, 51, 53]. Those with positive attitudes reported behaviours that helped preserve their independence [25, 35, 48, 49, 53]. Maintaining independence meant making their own decisions [25], or doing simple tasks [35, 53]. Being positive also enabled resilience in adapting to shared surroundings [27, 31, 35, 41-42, 46, 51, 53-54]. This resilience supported their sense of self efficacy, allowing them to thrive in the care home, quote 1 [51]. However, accepting care home life requires both positivity and a strong sense of self and awareness, quote 2 [46].

Acceptance enabled a strengthening of internal resources [27, 41, 44, 46, 49, 53], which may contribute to living well in care homes, despite restraints. Residents reported actively making decisions to adapt certain behaviours in order to lead a good life, quote 3 [53].

Connectedness with others

Connectedness and involvement with others, (n=21 studies) was integral for good care home life [24-27,48, 31, 33-35,38, 40-42, 44-45,48-50, 52- 54]. These connections represented social ties that either reinforced acceptance or distanced residents from care home life. Having peer residents contributed to friendships [25, 33, 49, 50], belonging [25, 32, 35, 37], and reassurance of being important to others [25, 27, 31, 33, 46, 50]. Lack of peer residents impinged on privacy, loneliness, boredom, autonomy and self-identity. Less impaired residents described withdrawing from relationships with other residents to maintain privacy [38-41, 52,]. However this led to loneliness and isolation, quote 4 [52]. Privacy was also affected by more impaired residents coming into their room unannounced or taking their possessions [37, 41, 52]. A lack of peer residents was seen as a reflection of how “far they had fallen”, a representation of their reduced circumstances [32, 37-38, 49, 52]. Thus, close relationships with peer residents contribute greatly to connectedness within the care home.

A reciprocal relationship with staff also contributed to good care home life. Where staff provided emotional or psychosocial care e.g. by sharing their own life, quote 5 [26], residents reported this affirmed respect and feeling of worth [24, 26, 32-33, 35, 38, 42].

The final aspect regarding connectedness revolved around changes in the resident-family relationship. For some the care home served to relinquish any feelings of burden [25, 30-31, 35, 46, 49], representing a sense of freedom and a way to re-establish familial roles, quote 6 [25]. For others, the care home represented a place to regain some independence [46].

A Homelike Environment

The majority of studies reported that factors within the care home environment facilitated acceptance [25, 27, 29-30, 32-33, 35-36, 39-40, 42-45, 48-49, 52, 54]. A homely physical environment [25, 27, 29, 32-33, 35, 39-40, 42-44, 48-49, 52-] ensured continuation of their QoL, allowing a smoother transition from home to care home. Having one’s own room and bathroom, enough storage and a quiet place [35, 37, 39-41, 45, 48, 51], facilitated residents’ abilities to exercise control quote 7 [27]. When a homelike environment is absent, quote 8 [45] a sense of institutionalised living occurs [29, 31-32, 37, 39, 42, 51-52]. The home is described as regimented and restricted, where daily life is routine and boring [30, 32, 40, 42, 45-46, 51-53].

 Meaningful daily life, characterised by the care home providing opportunities to go out [27, 42, 53-54] and appropriate activities [35, 40, 42, 49] influenced QoL by allowing autonomy. Care homes providing variety in how residents spent their day, allowed greater feelings of control [25, 28-29, 32, 35, 40, 45], preventing helplessness, quote 9 [49]. A meaningful daily life and homelike environment both emphasise the importance of the care home as a home, recognised in conjunction with the care home as a place that also provides care.

Caring practices

How care is provided has a significant influence on resident’s experiences [24-29, 32-33, 35, 37, 39, 44, 46-49, 52]. Residents needed to feel their needs were adequately met without carers rushing off to the next task [24, 28-29, 35, 37, 46, 48], as this can leave residents feeling vulnerable [33, 39, 46, 48] and helpless, quote 10 [33].

Carers’ competence and caring attitude, quote 11 [26], can contribute to positive care home experiences [24-27, 35, 39-40, 46-47, 49,]. Carers who knew their residents [24, 26-27, 48-49], their personal needs [26-27, 41], and an understanding of their life story [24,33,48] helped residents to be seen as both the person they are and once were, fostering their self worth, quote 12 [42]. Residents also reported that feeling safe [27, 35, 41, 43, 46, 51-52] combined with staff continuity [27, 32-33, 49] led to rapport and trust, ensuring a feeling of attachment [27, 32-33, 49, 50].

Discussion

This systematic thematic review found four key themes that affect good QoL in care homes: acceptance and adaptation, connectedness, homelike environment and caring practices. In particular, the theme *caring practices* echoes previous research where care home resource constraints affect older peoples’ QoL, and where quality of care is still the caregiver’s primary concern [10, 55]. This review also supports and extends the finding that a positive approach to living in care homes is associated with effective coping and adaptation [56]. More importantly, this review is the first, to our knowledge, to provide a synthesis of qualitative studies of various groups of people living in care homes.

Moving to a care home can change a person’s ‘psycho-physical’ balance [57], resulting in feelings of worthlessness and uselessness [58]. The first theme, “acceptance and adaptation”, demonstrated the importance of residents’ own attitudes, where residents taking an active stance in daily living felt more control of their lives [26]. This is supported by literature on older people, where adaptation in the face of changes was essential for, ‘feeling of anchorage to life’ [59]. For residents in care homes, a response shift [60] may occur, where those who constantly appraised their interactions with others and their environment, explicitly addressed changes they had to make in order to adapt effectively to their new lives. Whether this is due to changing expectations with age, or adaptability in the face of significant changes is difficult to ascertain, and further research is needed. Our findings suggest that carers can promote successful adjustment by communicating the impact of ‘institutional’ living on residents, and, providing a positive mindset. The second theme, ‘connectedness with others,’ demonstrates the importance of appropriate peer relationships [35]. This is also supported by studies on older people where quantity and quality of social engagement was found to prolong a person’s life [61].

A homelike environment where carers treat residents with respect, taking into account their individuality and identity [59], can reduce the impact of ‘institutionalisation’ [10, 62]. In care homes, routines are often designed to maximise the quality of care, with little room for negotiation and individualised care. However when some control was given to residents, this contributed to a sense of well being. Even the illusion of perceived control [63] can help an individual to interact successfully with their environment. However, whilst competent carers are important, *considerate care* is equally important [64], and promoting autonomy and independence depends on the nature of the caring relationship between staff and residents.

Methodological Issues

Many studies [n=11] reported that staff identified suitable participants, and provided little information regarding *who* carried out the research. Thus response, gender, and selection biases may have occurred. Only a third of studies reported residents’ ethnicities, although residents’ race is related to QoL [65].

Almost three-quarters of people in care homes have dementia [66] yet few studies have *qualitatively* assessed QoL in this population. Cognitively impaired individuals are seen as vulnerable and incapable of making decisions [67]. However, the studies reviewed demonstrate that people with dementia can voice their concerns [31, 34], echoing findings in acute care setting [68]. Thus more research is needed in this client group.

Only 17 studies in this review adequately reported recruitment methods and descriptions of care homes. This raises concerns about the generalisability of findings. Research has shown, for example, that care homes in rural areas are more comfortable, and that private facilities provide better dignity, security and lower levels of dissatisfaction [69, 70].

Strengths and limitations of the review

We used available qualitative methodological checklists for evaluating study quality, and synthesized findings using an established method to consider the original theoretical perspective of each study and authors’ interpretations. We also contacted authors where information was missing. However, not searching the grey literature and limiting studies to English, may have excluded some relevant literature.

Future Research

Only three studies included the views of younger residents i.e. <65 years of age. Some previous studies report no age differences in residents’ QoL [71], whilst others report [65] better QoL in older residents. QoL domains may also vary in priority according to age [67]. However the findings from a review of social discourse with younger care home residents with neurological and physical disabilities paralleled many of our key findings e.g. the importance of peer residents and staff relationship reciprocity [72].

As demonstrated with the four key themes of this review, a relationship-centred approach to care [73] is highly desired by residents. However, this requires the well-being of both staff and residents, and examination of the philosophy and values of the administration as these will undoubtedly affect the psychological milieu (or well-being) of all who live and work there [45]. This review did not look at the influence of care homes’ mission statements on QoL. Evidence suggests care home workers may view QoL differently from the mission statements [74].

We acknowledge that there are enormous economic, social, and cultural barriers that militate against the easy operationalisation of our recommendations. The reasons behind these barriers were not the explicit focus of our review, and are beyond the scope of this paper. However, these seem to be centred on the issues of lack ofstaff, training, and supervision [33, 45, 46]**.** Nevertheless,further qualitative reviews that specifically focus on the barriers to adopting these recommendations may address these issues more explicitly. Furthermore, although we have limited our recommendations to those that directly link in with our main findings, a qualitative study that specifically examines recommendations from the perspectives of service users, staff, and others involved in service delivery is useful, and may address these issues more directly.

Conclusion

This is the first systematic thematic review consolidating the views of people in care homes. For good QoL in care homes, there needs to be an understanding of the residents’ attitudes towards living there, and how factors within the care home impact upon their attitude. This echoes quantitative research where psychological functioning and social support were most strongly correlated to resident satisfaction [64]. Care homes need to make allowances to the care home environment to more closely align with residents’ personal preferences and meanings [73], e.g. match compatibility of roommates to promote meaningful engagement [75]. Care staff providing both practical and emotional support can enhance residents’ QoL. Organizational policies need to support this by maintaining continuity of care and less rigid time schedules and routines [45]. Capabilities of residents must be promoted and valued, to redefine the care home as one that promotes choice, not one that simply takes it away.

Key Points

* This is the first systematic thematic review of factors affecting good quality of life in care homes.
* For a good quality of life in care homes, four key themes are necessary; the person’s ‘acceptance and adaptation to their living situation’, their ‘connectedness’ with others, living in ‘a homelike environment’ and carers displaying ‘caring practices’.
* Previous research shows that people with cognitive impairments can successfully self report on their quality of life [76]. More qualitative research is needed within this population, especially with people with dementia.
* Care homes need to provide a ‘home’ that is person centred for each individual, using a carer relationship-centered approach that examines the personal preferences of each person to allow autonomy, self identity and independence to be maintained.

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Supplementary Data

Supplementary data are available at Age and Ageing online.

The very long list of references supporting this review has meant that only the most important are listed here. The remaining references are available on the journal website http://www.ageing.oxfordjournals.org/ as Appendix 3.

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Tables and Diagrams

Diagram 1: Flow Diagram of study retrieval.

55 full papers

31 papers included in review

22 papers excluded for not meeting inclusion criteria

993 excluded on method

1048 citations received from electronic searches, bibliographic searching, titles and abstracts screened

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| **Table 1: Descriptive Details of Studies in Review**Study, Country and Type of Resident | Quality Score out of 7 | Sample Description & Recruitment | Aims | Data Collection Methods and Analysis |
| Asmuth (2004) USADescription of home: Four long-term care facilities (3 for profit and 1 non-profit) with at least a 100-bed capacity.Age Group=late 60’s to 102, | 5 | Residents were chosen by staff .N=19Gender= 37% maleEthnicity: Not Reported | Whether interpersonal relationships could develop and be sustained between staff and residents within long-term care facilities. | Structured, non leading questions were used.Grounded theory methods and constant comparative techniques.  |
| Ball et al. (2000)USADescription of home: Homes were included that specialized in Alzheimer’sAge Group= 65-85 | 7 | The purposive sample chosen by staff consisted of 1 person from each of the 17 homes.N= 55, Gender= 11% maleEthnicity: All but one was White. | To address the knowledge gap about what assisted living residents deem most important to their day-to-day life. | One to one structured interviews. Grounded theory approach.. |
| Bergland & Kirkevold (2005)NorwayDescription of home: Wards had a mix of people with mental and physical impairmentsAge Group=74-103 | 7 | A purposive sample was used. N=26, Gender= 33% maleEthnicity: Not Reported | To examine the specific aspects of resident-caregiver relationship to thriving and whether a personal relationship to specific caregivers is essential to thriving in a care home. | Participant observation and open-ended interviews. Thematic analysis.  |
| Bergland & Kirkevold (2006)NorwayDescription of home: Wards had a mix of people with mental and physical impairmentsAge Group=74-103 | 6 | A purposive sample was used. N=26,Gender= 33% maleEthnicity: Not Reported | Investigate mentally lucid residents’ perspective on what contributes to thriving in a care home. | Participant observation and open-ended interviews. Thematic analysis.  |
| Boyle (2004) Northern IrelandDescription of home: Care homes - no further detailsMean Age= 82.8 | 3 | Recruitment by care home manager. N=251, Gender= 35% maleEthnicity: Not Reported | The extent to which the subjective quality of life of older people- particularly autonomy- varied according to the type of setting.  | A structured interview schedule Thematic Content Analysis. |
| Byrne (1993)AustraliaDescription of home: Profit, community and religious care homesAge Group= 72-93 | 7 | Random sampling by the nursing director of representative care homes. N=19, Gender= 47% maleEthnicity: All Australian with 2 ex-British gentlemen included.  | To develop a quality of life assessment tool for people in institutional care based on qualitative research.  | Open-ended interviews Grounded theory. |
| Chen et al. (2009) TaiwanDescription of home: The facility was for elders confined to a wheelchair- no further detailsAge Group=70-90 | 5 | Purposive sampling was used.N=17, Gender= 35% maleEthnicity: All Chinese | To explore the perceptions of group music therapy among older residents and its impact on quality of life. | Focus group methodology was used. Content analysis. |
| Clare et al. (2008)UKDescription of home: For people with DementiaAge Group= 59-96  | 6 | Purposive Sampling was used.N= 80, Gender= 15% male Ethnicity: Not Reported | The subjective experience of life with dementia in care homes to understand the psychological impact of being in this situation.  | Unstructured conversations. Interpretative Phenomenological Analysis [IPA].  |
| Cooney at al. (2009)IrelandDescription of home: Private and Public long term settings- no further detailsAge Group= 65-90+ | 6 | Purposive Sampling was used. N=101, Gender=67% maleEthnicity: Not Reported | To identify the determinants of QoL for older people in care homes, including exploration of mediating factors at personal and institutional levels. | Semi-Structured Interviews.Grounded Theory.  |
| Coughlan & Ward (2007)CanadaDescription of home: Care home for people of mixed cognitive abilitiesMean Age= 84.5 | 7 | Recruitment was by the care manager, the researcher and two research assistants. N=18, Gender= 28% maleEthnicity: All Caucasian | To find out residents' experiences concerning their care by following them as they were relocated from hospital style long term care facilities to new facilities.. | Participant observation and semi structured interviews.Grounded theory approach. |
| Droes et al. (2006)The NetherlandsDescription of home: For people with DementiaAge Group= 69-98 | 3 | The programme coordinators of 12 meeting centres made an inventory of the opinions of the persons with dementia who participated in the day club on QoL.N=143 Gender= UnclearEthnicity: Not Reported | To examine quality of life from the resident’s point of view and examine any differences with that of caregivers opinion.  | Focus Groups and Interviews.Grounded theory methods. |
| Edwards & al. (2003)AustraliaDescription of home: Care home- no further details given. Age Group: Not known.  | 2 | Recruitment methods are not stated. It is reported that 4-12 participants took part in a focus group. All residential homes were from the same aged care provider.Age, Gender, Ethnicity, unknown | To find out more about QOL in older residents from the resident's perspective as much as possible which then could be used to create a QOL measure.  | Focus Groups.Thematic Content Analysis. |
| Evans et al. (2005)USADescription of home: Care homes Facility- no further details given.Age Group= 20-93 | 5 | Purposive sampling was used. N=20, Gender=25% maleEthnicity: Not Reported | Determine the meaning of mealtimes to residents and connect that meaning with the social world in the care home to improve QoL. | Semi-structured interviews. Thematic Analysis Approach was used. |
| Fiveash (1998)AustraliaDescription of home: Residents experienced a broad range of physical and mental disorders in the homeAge Group=Not known | 4 | Purpose sampling.N= 8, Gender=25% male.Ethnicity: Not Reported. | What are the experiences of care home residents and give them an opportunity to reflect on their experiences.  | Open-ended interviews and participant observation. Thematic analysis.  |
| Hauge & Heggen (2007)NorwayDescription of home: Long stay Units for people with physical and cognitive disabilities.Age Group = 80-100 | 6 | The residents were assessed for their suitability- no details given. N=24 of which 9 were interviewed. Gender=Not ReportedEthnicity: Not Reported | To investigate the process and the degree to which the idea of the care home as a home has been realised. | Participant observation, interviews and studying documents. Phenomenological hermeneutic methods. |
| Herzberg (1997)USADescription of home: Floors were segregated according to cognitive ability in the care home.Age Group=Not known | 4 | A social worker and charge nurse identified potential residents.N= 20, Gender= Not ReportedEthnicity: Not Reported | To understand care home residents from the perspective of its residents. | Unstructured interviews.Grounded theory.  |
| Hikoyeda & Wallace (2002)USADescription of home: Residential Aged Care Facilities- no further details given.Age Group=75-100 | 6 | Care Home staff were asked to distribute recruitment flyers and make oral requests for participation.N=26Gender: 100% femaleEthnicity: Japanese American | To examine how ethnic features meet resident needs/preferences and their influence on the residents’ quality of life.  | Open ended interviews and participant observation. Grounded theory. |
| Hjaltadottir & Gustafsdottir. (2007)IcelandDescription of home: Two care homes where both cognitively intact and severely demented residents lived.Age Group= 76-93 | 5 | The nurse manager of each nursing-care ward assisted in recruitment. N=8, Gender= 25% maleEthnicity: Not Reported | To reveal the perceived QoL of physically frail but lucid older people. | Interviews. Hermeneutic phenomenology and thematic analysis. |
| Kaddar (2001)USADescription of home: Two story care home, upper floor severe dementiaMean Age= 85.5 | 5 | Purposive Sampling.N=14, Gender= 100% femaleEthnicity: All Caucasian and of Eng, Scot, Irish & Polish origin. | What are older people’s last stages of their lives in the care home like and what are the strength and resources they draw upon to cope with their circumstances. | Open ended interview. Thematic analysis approach.  |
| Le Low et al. (2007)Hong KongDescription of home: older people suffering from poor health or physical/mild mental disabilities, but who were mentally suitable for communal livingAge Group=65-92 | 6 | Purposive sample.N=20, Gender= 60% maleEthnicity: All Chinese. | The meaning of privacy and activities/practice/experience that supported/undermined privacy of Chinese older people in care homes.  | In depth unstructured interviews.Content analysis.  |
| Leung et al. (2003)TaiwanDescription of home: elderly people living in a care homeAge Group=65-86 | 7 | Purposeful sampling was used.N=44Gender= 50% maleEthnicity: All Chinese | To understand the components of QoL for older Chinese in residential homes or in their communities | Focus Groups. The transcripts were compared and discussed and grouped into 6 dimensions by the authors. Information carrying different meanings was sorted out and named according to various meanings. |
| McKinley & Adler (2005)USADescription of home: All care homes were non-profit and church related, no further detailsAge Group=80-101 | 4 | Purposive Sampling.N=21, Gender=33% maleEthnicity: Participants were described as all Euro-American which reflected the communities they had lived in.  | Elders’ perceptions of qualityof life in care homes. | Focus Groups and interviews. Transcripts were reviewedindependently. Observations were coded, listed, and sorted into categories. Re- readings of the transcripts yielded compatible themes that clustered together to organize key concepts. |
| Oleson (1992)USADescription of home: Care Home institutions. Age Group= 69-101 | 2 | Random sampling. N=26 Gender= 31% male.Ethnicity: Not Reported. | To explore and describe older care home residents’ subjectively perceived quality of life. | Semi structured interviews were used as well as quantifiable measures.  |
| Oleson et al. (1994)UKDescription of home: Three Care Institutions in south-west EnglandMean Age=84 | 4 | Convenience sampling. N= 10 Gender=20% maleEthnicity: All were Caucasian | Explore/compare perceptions of older residents and nurses to what things are important to a good QoL for residents and what nurses could do to promote residents' QoL. | Semi-structured interviews Phenomenological approach.  |
| Ornstein (1997)USADescription of home: A large urban care home in an ethnically diverse areaAge: 65+ | 3 | Purposive Sampling.N=6 Gender, Age, Ethnicity not reported. | Contribute to understanding the care home environment, how it impacts on residents and how they subjectively perceive their QoL. | Participant observation and unstructured interviews. |
| Riazi et al. (2011) EnglandDescription of home: Mixed care homes for people of different abilities but specifically for people with Multiple Sclerosis. Mean Age=61 | 7 | Non-probabilistic purposive sampling.N=21Gender=52% maleEthnicity: All were Caucasian except for one who was black.  | Explore how residents with Multiple Sclerosis perceive their QoL in the care home, and to identify ways in which they may enjoy good QoL. | Semi-structured interviews.Grounded theory. |
| Robichaud et al. (2006)CanadaDescription of home: People who had a range of disabilities i.e. MS, Stroke, Dementia, Macular Degeneration, Fraility. Mean Age/ SD= 82.5, ±8.5 | 5 | The nurse in charge identified suitable residents.N=19, Gender= 26% maleEthnicity= Not Reported | To identify personal and environmental characteristics that describe the best substitute living environment as perceived by residents and their families. | Semi-structured interviews. Grounded theory. |
| Stathi & Simey (2007)EnglandDescription of home: Care Home, no further detailsAge Group= 86-99 | 6 | Purposive Sampling. N=14Gender=14% maleEthnicity=Not Reported | To explore the exercise experiences of care home residents who participated in an intervention in relation to their QoL.  | Semi-structured interviews. IPA. |
| Tsai & Tsai (2008)Taiwan.Description of home: Care Homes, no furher details. Age Group=65-97 | 7 | Purposive Sampling.N=33, Gender= 39% maleEthnicity=All Chinese | To explore the living experiences of older care home residents. | Focus groups and in-depth interviews. Thematic analysis.  |
| Walent (2008) USADescription of home: Two care homes, one private for-profit and the other government sponseredMean Age= 81.9 | 7 | Purposive and snowballing techniques. N=17 Gender= 35.3% male. Ethnicity: Not Reported | To understand and articulate the experience and dimensions of doing well in older care home residents. | Interviews and participant observation. Grounded theory methods and hermeneutic analysis.  |
| Wolkenstein & Butler (1992)Country: USDescription of home: Care unit in retirement homeAge Group= 71-90 | 1 | Purposive Sampling.N=117 of which 16 participated in focus group. Gender=Not ReportedEthnicity: Not Reported | The aim of the study was to explore the QoL in the daily lives of the older residents.  | Analysis of a questionnaire, opinion survey, and a focus group interview. Content analysis approach. |

Table 2: Resident quotes for each of the key themes.

|  |  |
| --- | --- |
| Theme | Quote |
| Acceptance and Adaptation to their living situation | *1) ‘You'd never believe when I came here, I couldn't walk. But being left on my own, in my own room, I was determined to walk round the room and then the corridor, and things like that.’[51].**2) ‘Once you realise you need help, you must have the attitude that it's good to have someone take care of you. That's hard to appreciate, to think that it's good, when you know how confined you are. At first you don't. There's a bitterness to get over.' [46].**3) ‘Well see, um, these people I'm gonna have to deal with...I'm gonna have to deal with 24 [hours] a day, seven days a week. I can't make them mad and they can't make me mad...if we want to get along. So the best things for us to do be just like a bunch of ball bearings. We rub against each other, we polish each other.’* [53]. |
| Connectedness with Others | 4) ‘ *In my opinion, most of the residents can’t speak. Like the person in the bed next to me, she can’t speak. And in that room, four persons live in that room and none of them can speak...Furthermore, those who can speak may feel a barrier to communicating because of age difference...You ask, ‘Who can I speak with?’*. [52]5) *‘[Caregiver] can come into my room and tell me about her mother. You know their family...and then they tell you. I appreciate that very much. So I know more or less about all the caregivers' family affairs.’* [26].6)*‘ I don't want to live with them. I wanted to be independent...I wanted them to have their freedom and not be tied down and feeling obligated to me at all.’* [25]. |
| A Homelike Environment | *7) ‘I am very grateful that my room is big enough so that I have space for some private furniture. To have my own bathroom and toilet is the best. [27]**8) ‘The all white, all-the time, looks like a hospital.....But here what do we look at?- just those old bare walls. And it's not inviting.’ [45]*9) *‘And you, you can go out as well so, so it's a lot knowing that you can, you don't even necessarily go over to places but you can, it means something.’[49].*  |
| Caring Practices | 10) *‘they are expected to get everybody out to the table by 8.30 and it's pretty hard...they are too short staffed. Very short staffed. And they come to look after you and they run and leave you sitting there. They have no choice....maybe she's on the toilet, or he's on the toilet or something’*[33]. 11) *‘She takes care of everything and listens to me when I am talking. I think their carefulness towards people. That they think of the patients above all. That I think is the most important.’*[26]. 12) *‘They make me feel like family sort of... And I feel at home with them and that makes me feel that they feel at home with me’* [42]. |

Table 3: The contribution of key themes from each study.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Study | Quality Score | Acceptance and Adaptation | Connectedness with Others | A Homelike Environment  | Caring practices |
| Asmuth, (2004) | 5 | x\* | x | x | Reciprocal relationship with staff, caring staff, too busy, rude.  |
| Ball et al. (2000) | 7 | Being content with care home situation. | Friendship with residents, relieving burden from family, feeling lonely. | Meaningful activities, cleanliness, food, autonomy, privacy. | Caring attitude. |
| Bergland & Kirkevold. (2005) | 7 | x | x | x | Safety, carers ‘knowing’ & interested in them, being skillful & knowledgeable, continuity. |
| Bergland & Kirkevold (2006) | 6 | A positive attitude helps thriving. | Positive relationships with residents, family input.  | Meaningful activities, to go outside of home. | Staff carefulness towards to residents, having a relationship with staff. |
| Boyle (2004)  | 3 | x | x | Autonomy- being given a real choice. | Staff too busy to give choice, waiting for staff. |
| Byrne (1993)  | 7 | x | x | Institutional food, boredom, aesthetic environment- personal space, noise, autonomy, privacy, rules.  | Caring staff, lack of staff. |
| Chen et al. (2009)  | 5 | Persevere with life.  | x | Meaningful activity, routine, boredom.  | x |
| Clare et al. (2008) | 6 | Sense of loss of own situation, making do best they can. | Positive relationships with residents, more impaired residents, family, lonely. | Boredom. | x |
| Cooney at al.(2009) | 6 | Make the best of it, learning to adapt. | Positive relationship with residents, family visits.  | Autonomy, routine, privacy, boredom, purposeful activities. | Caring, kind and helpful staff, too busy, continuity.  |
| Coughlan & Ward (2007) | 7 | Living each day as it comes. | Friendship with residents, family, lack of peers. | Meaningful activity, boredom, noise, privacy.  | Continuity- loss of staff, reciprocal relationship, staff busy, competence, safety.  |
| Droes et al. (2006) | 3 | x | Family nearby, companionship. | Autonomy, sense of aesthetics in environment, enjoyment of activities.  | x |
| Edwards et al. (2003) | 2 | Determination to make the best of it.  | Relieve burden on family, loneliness due to lack of peer residents.  | Meaningful activity, privacy, appropriately sized bedroom and bathroom, autonomy. | Safety and security, competent staff, relationship with staff, staff too busy,  |
| Evans et al. (2005) | 5 | x | Relate to other residents. | Homelike mealtimes and food.  | x |
| Fiveash (1998) | 4 | Giving up, waiting to die- feeling hopeless. | Being afraid of residents, lack of peer residents. | Lack of privacy, boredom,. | Staff too busy, rude.  |
| Hauge & Heggen (2007) | 6 | x | Reciprocal relationship with staff, lack of peer residents- infringes on privacy. | x | x |
| Herzberg (1997) | 4 | x | Lack of peer residents. | Having homelike food , noise, lack of privacy- roommates.  | Carers actually care, lack of technical knowledge. |
| Hikoyeda & Wallace (2002) | 6 | x | Incompatibility among residents.  | Boredom, lack of activities, privacy of own room, autonomy. | Staff too busy, lack of caring attitude- aloof and stoic. |
| Hjaltadottir & Gustafsdottir. (2007) | 5 | Acceptance with care home life.  | Lack of peer residents, relationship with family.  | Privacy. | Safety, personal needs met and acknowledged. |
| Kaddar (2001)  | 5 | Acceptance with care home life.  | Relieve burden on family, positive relationship with family.  | Institutionalised food, variety of activities, routine life, aesthetic environment, privacy, autonomy,. | Reciprocal relationship with staff. |
| Le Low et al. (2007) | 6 | x | Problems with residents. | Privacy. | Safety.  |
| Leung et al. (2003) | 7 | Positive mindset.  | Seeing Family.  | Adapted environment, sleep. | Caring staff.  |
| McKinley & Adler (2005) | 4 | x | x | Homelike food, institutionalised environment, autonomy, privacy.  | x |
| Oleson (1992)  | 2 | Right attitude to receive help. | Mixing with residents, family relationships.  | Roommates matched for compatibility, routine, autonomy.  | Safety, caring, lack of staff,.  |
| Oleson et al. (1994) | 4 | Being agreeable. | Proximity to family.  | x | Caring attitude. |
| Ornstein (1997) | 3 | Maintaining independence. | Good friends.  | Privacy, spacious room.  | Reciprocal relationship, caring, too busy.  |
| Riazi et al. (2011) | 7 | Acceptance of living in care home, making the best of it.  | Relieve burden on family, friendship with other residents, lack of peers.  | Feeling safe, loss of activities did previously, spacious environment.  | Carers busy, perceived competency by knowing illness, continuity.  |
| Robichaud et al. (2006) | 5 | x | Cohesive in relationships with others. | x | Perceived competency through technical (nursing) acts and attitudes, staff continuity. |
| Stathi & Simey (2007) | 6 | Leading a reasonably happy existence.  | Companionship with other residents. | Boredom- restricted.  | Safety and security.  |
| Tsai & Tsai (2008)  | 7 | x | Relationship with family, lack of peer residents.  | lack of variety of food, lack of activities, boredom, regimented life.  | Safety, lack of caring from staff. |
| Walent (2008)  | 7 | Making the best of it, maintaining independence.  | Lack of peer residents,  | Privacy, routine life.  | x |
| Wolkenstein & Butler (1992)  | 1 |  Attitude in life, coping with adjustment.  | Having good companionship.  | Meaningful activities, Going out.  | x |
| x\*=not mentioned |  |  |  |  |  |

n PEOPLiew to include the voewdential care. ning f life. residents or carers. of life.

Appendix 1

In WoS, Cinahl, EMBASE and AMED, (i) search terms ‘interviews’ and ‘qualitative research’ were combined with the Boolean operator ‘OR’;(ii) search terms ‘Nursing Homes’ and Care Homes’ were combined with the Boolean operator ‘OR’; (iii).The search term ‘quality of life’ was searched and the results of searches (i) and (ii) were combined with this using the Boolean operator ‘AND’.

Appendix 2

The studies were coded according to, ‘the most basic segment, or element, of the raw data that can be assessed in a meaningful way regarding the phenomena’ [26 ]. The initial re reading of each study allowed the text of individual studies to be treated more as a whole while the major themes and categories were identified. We sought to reveal the analogies between the studies, indicating those that may be reciprocal, stand in opposition to one another, or taken together may represent a cohesive argument (25, 27). That is studies were translated into one another, comparing metaphors, concepts and the interaction of one account with those of other accounts.

Appendix 3

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