

Functional decline in residents living in nursing homes: a systematic review of the literature

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Keywords:

Activity of daily living

Functional decline

Nursing homes

Systematic review

Instruments

Running head: Functional decline in residents living in nursing homes

Abstract

Objectives: To describe the functional dependence progression over time in older people living in nursing homes (NHs).

Design: A systematic review of the literature was performed. Studies involving ≥ 65 year-old- individuals living in NHs, describing their functional decline, improvement or stability in Activity of Daily Living (ADL), were eligible. The search strategy was applied in MedLine, Cochrane, CINAHL and SCOPUS databases; aimed at identifying an unbiased and complete list of studies, searching by hand was also performed. The methodological quality of the 27 studies included was assessed.

Results: Functional trajectories were documented mainly through multicentre study design including sample size ranging from two to 9,336 NHs, from 1983 to 2011 throughout a single or multiple follow-ups (> 20). The average rate of decline was expressed in different metrics and periods of time. From three months with a decline of -0.13 points out of 28, to six months (-1.78 points out of 2829) to 1.85 years (-0.5 points out of 6). Eating and toileting were the most documented ADLs and the decline is around 0.4 points and 0.2–0.4 points out of 5 a year, respectively. Among the covariates, individual factors such as the cognitive status were mainly considered, while only 13 studies considered facility-level factors.

Conclusions: Findings report the slow functional decline mainly in women living in US NHs, in years when residents were admitted with a low or medium degree of functional dependence. Considering that in recent years residents have been admitted to NHs with higher-level functional dependence, studies measuring each single ADL, using standardised instruments capable of capturing the signs of decline, stability or improvement are strongly recommended. Among the covariates, evaluation of both individual and facility-level factors, which may affect functional decline, is also suggested.

Approximately 20% of the population suffering from functional limitations aged >65 living in European countries and around 1.4 million US citizens receive long-term care in Nursing Homes (NH); over the next decade the occurrence of individuals with functional limitations is projected to increase by about 120% at the worldwide level, and those receiving care in institutions will rise by an average of 130%.¹⁻²

Functional decline has been documented as a predictor of long-term institutionalisation³ and its continuing evaluation after NH admission is considered a core measure informing the quality of care offered.⁴ Data on functional decline in each activity of daily living (ADL) can also inform policy decision-makers in redesigning care priorities and services.⁵ However, while data is available on the functional status trajectory of community-dwelling older people, little is known regarding individuals living in NHs where the facility environment, in addition to individual factors, may increase, accelerate⁶ or attenuate the decline based upon the nursing, rehabilitation and medical services offered.⁷

Physical functional status is defined as the level of basic activities (ADL) performed by an individual to realise the needs of daily living in different dimensions of life (physical, psychological, social, spiritual, and intellectual).⁸ The process of functional decline follows a hierarchy:⁹ early-loss ADLs (dressing and personal hygiene) decline first, then middle-loss ADLs (toileting, transfer and locomotion) while at the end late-loss ADLs (bed mobility and eating).⁹ Ageing, gender, ethnicity, chronic conditions, cognitive impairment, malnutrition and poor social engagement have been recognised predictors of functional decline and, more recently, facility-level factors have been also acknowledged as predictors.^{10,11} The consequences of functional decline have been reported as poor quality of life, poor physical health, repeated hospital admissions, as well as a predictor of mortality.¹⁰

Since the 1980s,¹² functional decline has been considered a measure that should be considered to monitor the occurrence of adverse outcomes in NHs. Nevertheless, according to Rudman et al.¹³ data on functional decline collected prior to 1993 were not published; later, Sutcliffe et al.¹⁴ documented that relatively little literature existed about the natural history of functional changes that occur in older people after NH admission and data available reflected short-term evaluations or a synthesis of administrative data.

More recently in New Zealand, Boyd and colleagues² in their multiple cross-sectional study design evaluating functional decline in NH residents over 20 years found the proportion of those independent decreased from 18%

(1988) to 4% (2008), whereas those residents highly dependent increased from 16% to 21%, respectively. In accordance with the findings, while dependence in mobility, toileting, urinary and faecal incontinence and dressing demonstrated a significant increase, a different pattern emerged for residents requiring assistance in feeding: these were 35% of dependent residents in 1998 and 25% in 2008. In addition, the proportion of residents with cognitive impairment was higher (67%²), compared with previous data reported for long-stay residents (46%¹⁵).

In recent years, residents have been more likely to be admitted to NH in a worse condition than in the past. The increased presence of services in the community and the revision of eligibility criteria for NH admission, have redesigned the residents' care needs. Residents admitted in NH are sicker and closer to death than community-dwelling people; only 10–31% of newly admitted NH elders require minimal help in ADL tasks, and knowledge about how functional decline increases over time is lacking¹⁶ while instead rapid decline in the last three months of life is already well documented.¹⁰ In this context, measuring functional decline in NH residents is more challenging due to the reported major dependence at baseline, which is also a predictor of decline.¹⁷ Therefore, data available should be continuously updated, given that understanding functional changes in NH residents may affect different aspects of care: from staffing levels and skills-mix to staff education; from models of care delivery to preventive programmes aimed at intervening in the cases of specific impairments and groups of at-risk residents.

To describe the progression of functional dependence in older people admitted to NH over time, by summarising and critiquing the available literature, was the aim of this study.

Methods

Study design

A systematic review (SR) of the literature was performed. The findings are here reported on the basis of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement.¹⁸

Study selection criteria

The following study eligibility criteria were stated¹⁸

- Population: studies involving individuals from ≥ 65 years old admitted to NH with a certain degree or not of functional dependence, and living in an NH, were considered eligible. Those studies including disabled individuals in accordance with the MeSH definition, like those individuals with a certain degree of a physical, mental, or emotional pre-existing handicap, were therefore not included;
- Intervention: studies reporting data on individuals living in a) NHs as facilities providing nursing supervision and limited medical care, b) skilled nursing facilities providing skilled nursing care or rehabilitation services, and c) residential facilities as long-term care facilities providing supervision and assistance with ADL with medical and nursing services, were eligible. Therefore, those studies including both community and NH-dwelling individuals were also considered, but only data from residents living in NHs was considered. Instead, studies including residents admitted to chronic-care hospitals, to hospital nursing wards or to extended healthcare facilities, as well as those studies evaluating the effects of transition on residents across different NHs, were excluded.
- Outcomes: studies describing functional decline, improvement or stability, measured through self-reporting and/or as repeated evaluations by healthcare professionals using different tools, as well as reporting trajectories emerging from the analysis of available data sets over time, were eligible. Those studies a) reporting findings on tool(s) validation, b) evaluating the effects of tool implementation, thus assuming that introducing systematic assessments may increase the quality of care and reduce declines,¹⁹ c) measuring specific abilities (e.g. getting up from a chair²⁰) not included in the conventional set of ADL abilities; e) evaluating declines using instruments made up of items where ADLs were not distinguished from other aspects (e.g. confusion as in the case of Stockton Rating Scale²¹), and f) evaluating terminal trajectories before death (e.g.²²), were excluded.
- Study designs: longitudinal (prospective and retrospective) and interrupted time-series studies were eligible. Studies describing the effect of an independent variable (e.g. hospitalisation, infection, rehabilitation intervention) through a randomised clinical trial, a non-randomised clinical trial or a pre-/post-intervention

studies were considered eligible only when there was a control group who had not received any intervention and the outcomes were consistent with the aims of this SR. Studies documenting the repeated evaluation of functional status from an NH admission to death with multiple cross-sectional approaches,⁵ were also excluded.

Search methods

The search terms were identified as follow: ('Activities of Daily Living' AND 'nursing homes', 'nursing homes' AND 'Activities of Daily Living' AND 'Aged'[MeSH]) AND 'Aged 80 and Over', AND 'Longitudinal Studies', 'nursing homes'[MeSH] OR 'Skilled Nursing Facilities'[MeSH] OR 'Homes for the Aged'[MeSH]) AND 'Prospective Studies'[MeSH], (Nursing Homes) AND (functional decline OR activity daily living dependence) AND (retrospective OR longitudinal studies); limited for aged (≥ 65 years) and language (English). The search strategy was applied without any limitation regarding time. Terms were combined as MeSH and Text Words in MEDLINE (1966) and as text words in the Cochrane Library, and in the CINAHL and SCOPUS databases. The search strategy was applied in March and repeated in December 2014. Aiming at identifying an unbiased and complete set of relevant studies, a search by hand was also performed to review the references of the studies included; authors conducting large studies (e.g. ²³) to discover whether unpublished documents pertinent to the aims of this SR were available, were also contacted.

In the preliminary stage, the search strategy was as comprehensive as possible in order to include the greatest number of studies and then gradually narrowed according to the inclusion and exclusion criteria. Duplicated studies were removed from the list. Then, titles and abstracts were screened according to the inclusion and exclusion criteria by four researchers working in pairs. Studies were categorised into three groups: 1) eligible study, when it was considered pertinent according to the inclusion and exclusion criteria; 2) ineligible study, when it was considered not pertinent to the study aims; and 3) not evaluable study, when it was not possible to detect from the title or the abstract its pertinence with regard to the inclusion/exclusion criteria adopted. Agreement on article inclusion was between 93% and 99% for the studies screened. Disagreements were discussed with a third researcher and the decision was made when full agreement was achieved.

Authors of eligible studies including for example, subgroups of populations pertinent to the aims of this SR, were contacted by email at least twice, with the aim of collecting relevant data. When no response was obtained and the study was not evaluable, it was excluded. For authors who responded, the study was included or not according to the answer(s) obtained. The inclusion/exclusion process for retrieved studies is reported in Diagram 1.

Data extraction and quality appraisal

Four researchers working in pairs read the included studies carefully and performed the data extraction with a grid reporting the following items: a) study identification (author, citation), b) study features (study setting, study design, sample size, baseline, follow-up, withdrawals), c) instruments adopted for data collection and the data collected, as global scores or specific scores in each ADL which were categorised in homogenous domains (e.g. toileting, locomotion/walking) in accordance with their hierarchy (early-loss, middle-loss and late-loss ADLs),^{9,24} d) individual/facility-level variables taken into consideration: the main variables considered as covariates both at the individual (e.g. cognitive status) and at the facility level (e.g. bed size) were recorded; e) the main findings of functional trajectory were reported in the metrics used by the study (e.g. average/month), and f) the role of individual/facility-level variables were also summarised in a descriptive fashion. Disagreements within researcher pairs were discussed with a third researcher.

The quality of the studies included was assessed using the criteria defined by Tooth et al.²⁵ that reflects design and interpretation aspects covering the study rationale and population, recruitment, measurement and biases, data analysis and the generalizability of the findings. Considering that not all criteria were deemed applicable to different study designs included in the present SR, as suggested by Tooth et al.,²⁵ a set of 15 items were considered in the quality evaluation process (list available from authors). Therefore, studies were categorised as high (scoring from 13 to 15), moderate (from 9 to 12) or poor (< 8) quality, as evaluated by two researchers independently.

Results

Methodological frameworks and quality of the studies included

A total of 27 studies were included, mainly adopting multicentre study designs including from two to 9,336 NHs, the majority in the US context (17; 62.9%) where some authors had also conducted multi-state studies.^{11,19,26-28} The baseline included a single year (e.g. ^{13,29}) or a period lasting a minimum of two years (e.g. ²⁸) to 10 years.³⁰

In general, studies documented ADL trajectories from 1983²⁶ to 2011³¹ during a single follow-up (3 months) or at multiple follow-ups (> 20) assuring therefore a short-term (3 months, e.g.⁴) and a long-term (58.7 months³²) description of functional trajectory in residents living in NHs. The majority of the studies were prospective in nature (17; 62.9%).

The main data source was the routine assessment database (20; 74.1%), a small proportion used only questionnaire-interviews or interviews (4; 14.8%), direct observation (2; 7.4%) or multiple sources (1; 3.7%). The ADL measures were based on items included in the NH Minimum Data Set (14; 51.8%), on the Care Dependency Scale (2; 8%) and on the Finch et al.³³ scale (2; 8%) while six studies were based on a miscellany of tools (e.g. Barthel Score, Katz Index). Three studies used single items.^{6,34-35}

The ADLs measured were, in order to frequency, eating (22/27), toileting (17/27), locomotion/walking (13/27), transferring (13/27), and dressing (12/27) followed by personal hygiene (11/27), continence and other (e.g. bed mobility 9/27) while the activity least measured was bathing (6/27). Between one^{6,34,35} and seven ADLs^{29,36} were measured by each study, an average of four across the studies.

Cognitive status (measured as dementia, cognitive impairment, high/low cognition), along with other individual factors (emotional, behavioural, clinical, social) were considered as covariates in the analysis. Variables associated with the NH facility such as bed size, mission and quality of care, were also evaluated in around half studies (13/27). The quality of the studies ranged from high to moderate: in Table 1, the main characteristics of included studies, grouped on the basis of the homogeneity instrument of assessment adopted, are shown.

Functional trends

Sample size ranging from 65³⁷ and 605,433 residents⁴ were included at baseline reporting with attrition rates ranging from 82.8%³⁹ to 5%^{6,35} while 15 (55.5%) studies evaluated the same cohort of residents over time, thus had no attrition.

Residents were on average aged > 79 years across all studies and the majority of residents were > 80 years old with the exception of Rudman et al.'s study,¹³ where some residents were younger (57.6% = 65–79 years). Most participants were female with proportions > 66.1%^{26,36} reaching 100% in Dijkstra et al.,⁴⁰ while three studies^{10,13,46} included men living in veteran NHs. However, two studies did not report age^{4,41} and three did not include gender data.⁴¹⁻⁴²

As reported in Table 2, the majority of studies (18; 66.6%) documented functional trends on the basis of global scores, and the remaining reported the decline of some specific ADLs such as eating, transferring or other.^{6-7,13,19,31,34-35,40,43}

In reporting the decline, 15 studies out of 27 reported their findings in averages; nine considered the amount of residents who have transited from one degree of dependence (e.g. low) to another (e.g. medium); the remaining three studies functional decline was reported in terms of incidence of episodes of degradation and in the likelihood of decline. Only five studies out of 27 documented the stability of ADLs^{7,14,26,34,41} or improvements in ADLs.^{7,26,30,34,41}

The average rate of decline was expressed in different periods of time. For example, from three months³⁶ with a decline of -0.13 points out of 28, to six months (-1.78 points out of 28²⁹) to 1.85 years (-0.5 points out of 6³²). Eating and toileting were the most documented ADL both as percentages and averages. A decline in eating was reported in 1.7% to 1.8% of the residents by Wang et al.⁴³⁻⁴⁴ and for 13.7% by Rudman et al.,¹³ both after 6 months; the rate of decline was similar to that reported by Phillips et al.,¹⁹ after one year (12.4%). Regarding toileting after six months, different rates of decline were reported: 6.3% and 3.4% respectively, in Wang et al.⁴³⁻⁴⁴ while in the Rudman study¹³ around 17.3% of residents had declined, more than Phillips et al.¹⁹ documented after one year (14.2%).

In a more detailed fashion, Caljouw et al.³¹ documented an average of 0.4 points of decline out of 5 in eating after 12 months, while hygiene was more stable (an average of 0.2 out of 5). More than ten years before, Dijkstra et al.⁴⁰ also detailed the average decline in eating which was found to be -0.73 out of 5 after 24 months, similar to that reported for toileting (-0.75 out of 5).

Discussion

Methodological frameworks and quality of the studies

Only four European studies developed in the Netherlands^{31,40}, Norway³⁹ and Switzerland,³⁰ were included, while five studies were conducted respectively in Israel,⁷ Canada^{6,35} and Taiwan.^{10,46} Therefore, the knowledge available describes the functional trajectory of NH residents mainly living in the US, where a minimum data set was introduced since 1990–92 as a basis for the routine assessment.²⁴ The lack of harmonisation of the measures adopted in the assessment of NH residents, at state level and at multi-state level (as in Europe), prevents further comparison and understanding of the outcomes in older individuals admitted in NHs.

The baseline periods of the studies included varied from 1983 to 2011 and the majority were conducted between 1990 and 2004: few were performed before^{34,41} or after this period.^{6,10,31,34-35,46} Therefore, the functional trajectories documented date back to 2004: in recent years, admission to NHs has been delayed due to increased community services helping families to manage functional dependence, which has characterised NH admission as a prerogative for the most dependent people.² Continuing to study trends in functional decline from NH admission over time, is required for informing resource allocation, education and redesigning services.

Three patterns have emerged in the study design: a) studies describing the functional trajectory by reporting all evaluations in the database selected: in such cases all residents included were also evaluated at the end of the follow-up and no attrition rates emerged; b) other studies described the ADL trajectory as reported in one or more evaluations until the end of the established follow-up, progressively excluding those residents

discharged or dead. In such cases, studies reported the attrition rate which increases in relation to the entire duration of the study (longer studies report greater attrition); and c) two studies^{30,32} instead mirrored community studies including a cohort of residents with a number of evaluations based on their permanence in the NH, without defining the end of the follow-up a priori. Repeated measurement of ADLs in the same individuals implies dependence in data, and the large number of drop-outs due to death or transitions to other facilities, may generate unbalanced longitudinal studies, an issue that needs to be addressed in future studies.

Differences in the duration of studies have also emerged: there were short-term (3 months) to long-term (9–10 years) follow-up studies with a tendency for studies to last around 1.5–2 years. While in long-term studies the natural functional trajectory is captured, in those short-term, variations may be determined by the clinical conditions⁴ and by the excess of disability which is reversible e.g., when the resident is encouraged to perform ADLs or receive rehabilitation services.⁴⁶ The duration of the follow-up may also change the functional status description: the longer the interval, the more likely it is that change will occur. In addition, short-term studies including newly admitted residents can be influenced by NH admission itself that may improve functional status for those whose home care is no longer supportive. After the initial stage, changes in ADL might not vary over time given that residents may adapt to the setting;⁴⁷ therefore, while studies including short-term evaluations may have evaluated the effects of NH admission, those long-term evaluations may have described the degree of person–environment fit as the ability of the resident to adapt to the context. Therefore, the inclusion of facility-level, in addition to those individual-level variables already reported in all studies (e.g. cognitive status), is strongly recommended.

Studies have included heterogeneous groups of residents, just admitted to an NH (e.g.³²) to those who have been resident in NH for a certain period of time^{29,37} or who have received a predefined amount of assessments (e.g. at least two³⁰). Short-stayers (<3 or 6 months) were also included, often after hospitalisation. These groups of residents, may have different functional trajectories, and they may also be a differing probability of being discharged from a NH.²⁶

The number of assessments performed was also variable, from a single assessment to more than 20. Studies have also adopted incremental time-lag assessments that are more concentrated in the beginning of the study near to the baseline (e.g. after 1 or 2 months) and less so later (6 months, 9 months, 12 months)²⁶ or have

adopted non-homogenous intervals (after 5 and 9 months)¹⁴ or a period after admission (after at least 1 year, on average 2.1 years).¹¹ With an increase in time between assessments, researchers have more opportunity to describe the pattern of decline rather than incident episodes which may be ascertained in shorter intervals.²⁶ However, the lack of homogeneity in the number of assessments as well as in their intervals, prevents the accurate description of the functional loss/improvement for a consistent period.

The majority of the studies have used instruments already available in the NHs involved, as the minimum data set required for reimbursement and few authors adopted expert observation or interviews guided by standardised or non-standardised tools. In the case of interviews, residents tend to define themselves as more capable of performing dressing, toileting, locomotion and personal hygiene activities in particular, with respect to the evaluations reported by nursing staff. Assessment based on clinical observation rather than self-reported physical function is considered more reliable within high-risk groups such as residents with cognitive impairments.²⁹ On the other hand, in studies based on routine assessments derived from well-established instruments, a reduced rate of functional decline can be reported, given that the adoption of a tool may improve the quality of care and strengthen the vigilance of nurses in specific sub-groups of residents at risk of losing ADLs or who are already impaired.¹⁹ In those routine evaluations where care is overprotective or reported data is influenced by reimbursement issues, inaccuracies might also be introduced.

Studies have reported functional global scores, indicating summary counts (from 0 to 100 and from 0 to 28); a more detailed trend regarding specific ADLs has been described to a less extent (e.g. the functional decline of eating). The latter analytical staging approach is based on the assumption that residents develop dependence in some of the most difficult activities before easier ones and later, in the more complex activities such as eating.⁹ The global ADL score is a simple and compact measure but does not inform the profile of elder individuals and their needs.⁷ However, among the different tools used, two main types of instruments have emerged:

- additive systems: those measuring dependence by adding up the number of dependencies in a score. Among these, two examples are the MDS ADL Long (composed of seven items (0–28) and its short form (composed of four items, one early loss, two middle loss and one late loss (0–20)).

- hierarchical systems: those reflecting the process of disability and the hierarchy of ADL loss.⁹ In the ADL Hierarchy Scale (MDS) scores are given in accordance with the stage of the disablement process in which they occur. This scale includes four ADL, as in the MDS ADL Short Form, assigning lower scores to those early-loss instead of late-loss ADLs, with seven different categories combining different impairments.²⁴ The Katz Index could be placed in this group as the tool developed by Finch et al.³³ where a specific weight is assigned to each level of dependence (none, total) within each seven ADL measured. While a resident needing a little assistance in all ADL might be scored 2,406, if the need is total, the score might be as high as 5,431.

Hierarchical tools allow more precise identification of discrete impairment levels, while additive systems tend to be sensitive to minute shifts in residents' status: both types may be used to detect changes at the programmatic level, but clinically, the long forms are more successful than hierarchical ones.²⁴

Functional trends

In accordance with the findings, 27 studies have documented the functional trajectory including, at baseline, 981,837 residents living in an NH and 976,694 (99.4%) at follow-up. The majority of the residents were female and the average age was around 80 years, reflecting the already acknowledged NH residents' characteristics.²

From the findings, the functional decline in residents living in NHs seems to be slow as documented by Freedman et al.⁴⁷ in their SR on functional decline among community-dwelling elder adults in the US, where a decline of -1.55% per year to -0.92% was reported. More recently,⁴³⁻⁴⁴ a decline slower than that reported in the 1990s^{13,19} has been documented, possibly due to the worse functional dependence at NH admission determining a ceiling effect; but also to improvements in the quality of nursing care offered in NHs. In the past, when functional independence at NH admission was higher,² it was less challenging to describe the functional trajectory over time, due to the floor effect. However, functional decline may proceed at different speeds,¹⁰⁻¹¹ depending on the clinical condition of the resident and the facility characteristics.

Eating and toileting were the most documented ADL also reporting a slight decline, around 0.4 points out of 5 a year (around 0.8 after 2 years) and 0.2 out of 5 (0.8 after 2 years) according to Caljouw et al.³¹ and Dijkstra et al.⁴⁰ who used the same tool. These values should be considered when evaluating the effectiveness of interventions designed to prevent functional dependence in eating/toileting and conducting studies for long periods aimed at detecting the actual effects of interventions is recommended.

Early studies of functional decline documented the effects of a few covariates (such as cognitive impairments) and only recently studies recruited cohorts of people suffering from dementia³⁹ which is the major cause of admission to NH.^{3,47} In these individuals, independence is a challenge, given that they might have the ability to perform a task (executorial independence, such as eating) but several progressive cognitive impairments (e.g. the inability to express needs, to initiate eating) may compromise their independence. According to Neumann et al.,⁴⁹ ADL trajectory has become more relevant in individuals with mild or moderate dementia, which may determine a ‘backward transition’ or ‘reversal of clinical milestones’. This temporary decline, which does not constitute a stable decline, requires more sophisticated assessments,^{6,35} a profound knowledge of the history of the resident, as well as constant monitoring. In addition, longer follow-ups are required in order to capture real trends instead of transient declines.

More recently, studies have tried to develop more complex models of analysis, tracing the trajectory of dependence in a limited set of variables (walking, eating) and various individual and environmental factors.^{6,35} The variance in functional decline among NH residents is explained for 8–14% by facility-level variables and for 12% by individual characteristics;³⁶ therefore, there is a need to discover the complexity of factors underlying the risk of functional decline, in addition to those already discovered. Beyond the individual variables, facility-level variables should also be considered in further studies evaluating functional trajectory.^{6,35,36}

Conclusion

This SR has several limitations. Language and publication bias may have affected the findings; in addition, the huge amount of literature screened may have threatened the accurate identification of all relevant studies. In an attempt to prevent these biases, grey literature searching and multiple contacts with authors or

leaders in the field were performed. Furthermore, the literature search was performed twice and two researchers independently performed each phase, discussing any disagreement.

In accordance with the SR aims, studies regarding individuals living in NHs with pre-existing physical, mental or emotional disabilities/handicaps, were not included. Given that most of these individuals may live in NHs, further studies should include also these populations, exploring, whether or not differences exist in their functional trajectories as compared to those reported by elder individuals with a certain degree of decline at NH admission. In addition, given the variations in facility definitions (e.g. Nursing Homes, or “home for the aged”, and assisted-living facilities) and missions (e.g. rehabilitation services), were only recently a common definition has been agreed upon,⁵⁰ generalization of the findings across countries should be considered with care.

In accordance with the findings, elderly individuals living in NHs report slow functional decline, which is difficult to estimate precisely, due to the different measures adopted in the studies as global scores. With regard eating and toileting, the decline is around 0.4 points and 0.2–0.4 points out of 5 a year, respectively. Findings predominantly reflect the functional trajectory in women, living in US NHs, before 2010, when residents were admitted with a low or medium degree of functional dependence.

The emerging studies have documented, in order of frequency, late-loss ADLs such as eating and middle-loss ADL (toileting, transferring, locomotion/walking) while few early-loss ADLs such as dressing and personal hygiene have been reported. Summary scores may help in decisions regarding staffing needs, while specific scores may help in evaluating the effects of some interventions. Since residents who have higher levels of dependence in ADL may report slow and imperceptible changes over time, reporting every single ADL is suggested, using instruments capable to capturing which abilities decline, remain stable or improve and to decide the interventions to promote.

There is also a need to introduce compatible, valid and reliable assessment instruments across different systems and domains, to overcome barriers related to culture, history and approaches used to gather and use information. In addition to the adoption of standardised instruments administered on a regular basis, it is also necessary to focus attention on stability and improvements in residents' abilities rather than functional decline

which has been the mainly focus of the studies to date. In the analysis of covariates, evaluation of individual and facility factors such as the amount of staff, which can affect the functional trajectory, is also recommended.

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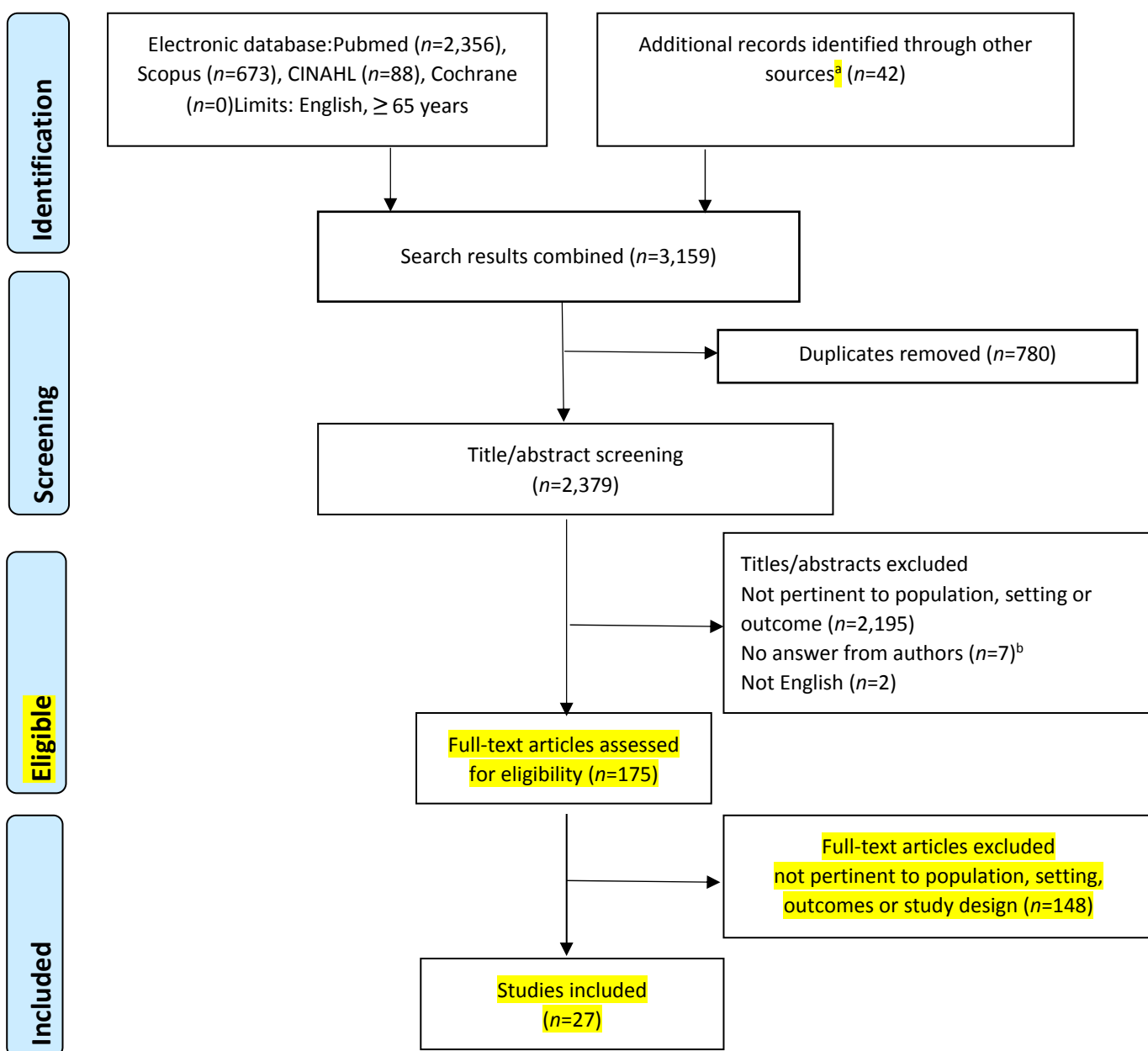
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Diagram 1

Studies retrieved, included and reasons for exclusion.¹⁸



^a ascendant and descendant hand-searching from: a) Doctoral thesis reference list, and b) reference list of included studies

^b in case of incomplete data (e.g. regarding sub-group of NH residents when studies included different groups of elderly people)

Table 1

Methodological frameworks and quality appraisal of the included studies, categorised on the basis of the data sources/instruments

Authors	Setting	Design	Baseline	Follow-up	Data Sources and Instruments	Early-loss ADLs		Middle-loss ADLs		Late-loss ADLs			Total score	Main Individual/facility-level variables	Study quality appraisal
						Dressing	Personal hygiene	Bathing	Transferring	Walking/locomotion	Toileting	Eating			
Banaszak-Holl et al. ³²	NHs (NR), USA	P	1999-03	every 3 m, -> 58.7 m	RA = MDS-ADL hierarchy		•		•	•	•	•	•	LSs (>180 days) newly admitted, cognitive status, clinical diagnosis	High
Bürge et al. ³⁰	90 NHs, Switzerland	R	1997-07	every 4 m ≈> 23.9 m	RA= MDS-ADL hierarchical		•		•	•	•	•	•	Rs with at least two assessments, cognitive status, depression, clinical conditions, Body Mass Index	High
Carpenter et al. ²⁹	NHs (NR), USA	P	2002	3, 6 m	RA = MDS-ADL Long Form	•	•	•	•	•	•	•	•	Rs (<90 days), moderate and severe dementia	High
Chen et al. ¹⁰	2 Veteran NHs, Taiwan	P	2006-10	3, 6, 9, 12, 18 m	RA + I = MDS-ADL			•		•	•	•	•	Rs, cognitive status, social engagement, pain, Resident Assessment Protocol (18 triggers, e.g. delirium)	High
Cole et al. ³⁷	10 LTFs, USA	DSRM	NR	3 m ≈	RA + I = MDS			•	•			•	•	LSs (>90 days), cognitive intact or with mild impairment, sense of coherence (SOC) index	Moderate
Li et al. ⁴	9,336 NHs, USA	R	2004	3 m	RA = MDS-ADL Short Form			•		•	•	•	•	LSs, diagnosis, medication, cognitive and behaviour impairments, facility volume	High
McConnel et al. ²⁷	NHs (NR), USA	R	1993-96	3, 6, 9, 12 m	RA = MDS-ADL Short Form	•	•	•		•	•	•	•	LSs, severity of cognitive impairment	High
McConnell et al. ¹¹	NH (NR), USA	R	1993-96	12 m at least (μ24 m)	RA = MDS-ADL Short Form	•	•	•		•	•	•	•	LSs (> 1 year) with at least four evaluations, cognitive status, comorbidities	High
Phillips et al. ³⁶	1,334 Fs, USA	R	2002	3	RA = MDS-ADL Long Form	•	•	•	•	•	•	•	•	Rs > 3 months, change in health, end stage disease, symptoms/signs, cognitive status, frailty, depression, facility variables	High
Phillips et al. ¹⁹	> 800 Fs, USA	P	1993-94	3, 6, 9, 12 m	RA = MDS summary Scale	•			•	•	•	•	•	Rs living in Alzheimer's SCU, in traditional unit, in SCU facility and non-SCU facility	High
Sloane et al. ²⁸	40 NHs and 106 AL, USA	P	1997-98	3, 6, 9, 12 m	RA + I= MDS-ADL Long Form	•	•	•	•	•	•	•	•	Rs, mild/moderate/severe dementia, comorbidities, behavioural problems, depression, social functions, NH/AL facility profile	High
Wang et al. ⁴⁴	377 NHs, USA	NE	2004	6 m ≈	RA= MDS-ADL Long Form		•			•	•	•	•	High cognitive status vs. low cognitive status, pain depression, continence, balance dysfunction and fall, comorbidity, medication, facility variables	High
Wang et al. ⁴³	377 NHs, USA	P	2004	6 m ≈	RA = MDS-ADL Short Form		•			•	•	•	•	LSs, 14 Rs-level variables (pain, depression; fall history) and eight facility-level control variables	High
Calijouw et al. ³¹	21 LTFs, NL, EU	P	2008-11	6, 12 m	QI = CDS	•	•		•		•	•	•	Rs, comorbidities (e.g. dementia)	High
Dijkstra et al. ⁴⁰	1 NH, NL, EU	P	1994	24 m	QI = CDS	•	•		•		•	•	•	Rs with Alzheimer's, behaviour, comorbidity, psychopharmacological drugs, sight/hearing	High
Frytak et al. ⁴²	69 NFs and ALFs, USA	P	1995-96	6, 12 m	RA + QI = Finch et al. scale	•			•		•	•	•	Rs (< 21 days), psychological well-being, pain, discomfort, health status (e.g. cognition), social variables, ALS vs. NH	High

Table 1
(Condt.)

Authors	Setting	Design	Baseline	Follow-up	Data Sources and Instruments	Early-loss ADLs		Middle-loss ADLs		Late-loss ADLs		Total score	Main Individual/facility-level variables	Study quality appraisal
						Dressing	personal hygiene	Bathing	Transferring	Walking/locomotion	Toileting			
Stark et al. ⁴¹	NHs (NR), USA	P	1988-89	10 m	RA = Finch et al. scale	•	•	•	•	•	•	•	Rs, behaviour, medical conditions (e.g. dementia), living situation pre-admission, medication, facilities size	High
Gillen et al. ²⁶	48 NHs, USA	P	1983-87	1, 2, 3, 6, 9, 12 m	RA= Katz Index	•	•	•	•	•	•	•	Rs newly admitted; LSs (>100 days) and SSs resident, physical, mental health diagnoses	High
Helvik et al. ³⁹	26 NHs, Norway	P	2004-05	12, 31, 52 m	I = PSMS							•	Rs with clinical dementia, comorbidities, sensory loss, psychiatric symptoms, psychotropic medication	High
Ouslander et al. ³⁴	8 NHS, USA	P	1987-88	0.5, 2, 12 m	MS							•	Rs newly admitted, dementia, depression, delirium, faecal incontinence, psychogeriatric examination	High
Porell et al. ⁴⁵	>500 NHs, USA	R	1991-94	3,6,9,12,15,18, 21, 24,27,30, 33, 36 m	RA= MMQ	•	•	•	•	•	•	•	Rs (remaining from 3 months to 3 years), mental status, medical condition, frailty, risk factors, facility variables (e.g., bed size, profit/non-profit)	High
Rudman et al. ¹³	69 NHs, USA	R	1992	6 m	RA= PAI				•	•	•	•	LSs (>6 m), bedsores, physical aggressiveness, behaviours, clinical diagnosis, facility variables (e.g. bed size)	Moderate
Slaughter et al. ⁶	15 NHs, CA	P	2006-07	15 days, 12 m	DO				•				Rs with middle dementia, comorbidities, Global Deterioration Scale, medication, facility variables	High
Slaughter et al. ³⁵	15 NHs, CA	P	2006-07	15 days, 12 m	DO					•			Rs with middle dementia, comorbidities, Global Deterioration Scale, medication, facility variables	High
Sutcliffe et al. ¹⁴	30 NHs and RHs, UK	P	1996-97	5, 9 m	I = Barthel Score							•	Rs newly admitted, cognition, depression, medical conditions, prescribed medication, Quality of Life	High
Walk et al. ⁷	54 Fs, Israel	R	1986-95	30 m	RA = SFA		•		•			•	Dependent Rs (staying 2 - 4 years), NH quality of care (0–100) based on state surveillance data	Moderate
Yeh et al. ⁵⁴	2 Veteran NHs, Taiwan	P	2006-10	3, 6, 9, 12	RA I= RUG-III ADL			•		•	•	•	Cognitive function, social engagement, pain assessment, RA (18 triggers, e.g. delirium)	High

^adata reported only for LSs residents; ^b according to the definition given to Adult Foster Homes, only those residents admitted and surveyed in NHs were included in this SR

ADL= Activity of Daily Living; NR = Not reported; ≈ = approximately; Rs = Residents; LSs = Long Stayers; SSs = Short Stayers; RAP = Resident Assessment Protocol
 Setting=AL, ALFs Assisted Living facilities, F Facilities, LTF Long-term facilities, NF Nursing Facilities, NH Nursing Homes, RH Residential Home, SCU Specialized Care Unit
 Study design= R Retrospective, P Prospective, NE Non-experimental, DSRP Descriptive Study Repeated Measures
 Baseline, Follow-up = m month(s); ->the follow-up was repeated as much as possible according to the permanence of the resident in the NH
 Source of data= RA Routine Assessment, QI Questionnaire Interview, I interview, DO Direct observation, MS Multiple source (medical record, residents, families and nurse aides interviews)
 MDS, ADL based on items included in the Minimum Data Set, Short form when comprising four ADLs (0–20), Long Form when comprising seven ADLs (0–28), and Hierarchical; PAI Patient Assessment Instrument, CDS Care Dependency Scale, MMQ Management Minute Questionnaire, PSMS Physical Self-Maintenance Scale, SFA Standardized Functional Assessment

Table 2ADL trajectory over time in residents living in NH: **main findings**

Author(s)	Baseline/ follow-up	Age Gender	ADL Trajectory	Main Individual/facility-level variables
Banaszak-Holl et al. ³²	3,634	≥85 = 45% F 71%	Baseline = 3.33 out of 6 (±1.62); after 1.85 years = deterioration by 0.5 points	↑ Higher cognitive impairment vs. lowest level of cognitive impairment; > 85 years; functional status at baseline
Bürge et al. ³⁰	10,199	80-90 = 49% F 70.3%	Degradation = 3,607 times out of 10,199 (35.4%), 0.22 event/person-year Improvement = 1,415 times (13.9%), 0.08 event/person-year	↑ (by hierarchical order) poor balance, incontinence, impaired cognition, undernourishment, hearing/ visual deficits, no daily contact with others
Carpenter et al. ²⁹	11,617/9,394	85-94=48-50% F 79.7%	Deterioration after 6 months = moderate cognitive impairment 1.78 points/28 (95% CI 1.67–1.91); severe impairment 1.70 (95%CI 1.59–1.83). 26% of Rs with moderate impairment declined in personal hygiene, dressing and toileting compared to around 21% with severe impairment Highest decline in eating was in Rs with severe impairment (38%) vs. moderate (29%)	↑ Cognitive impairment
Chen et al. ¹⁰	1,286/1,045	A 83 F 0%	Baseline MDS RUG-III ADL = 4.4 out of 18 (±1.5); after 1 year + 0.5 (± 2.2) 118 Rs (11.3%) developed significant functional decline	↑ LSs (>5 years), cerebrovascular disease, dementia, higher number of RAP triggers ↓ Better social engagement
Cole et al. ³⁷	65	A 79.9 F 80%	Baseline = average 14.0 out of 50; after 3 months 14.15	= High and low ability of successful response to stress
Li et al. 2010 ⁴	605,433	A 79.4–81.7 F NR	Unadjusted rate of decline after 3 months = 18.6% in the low-volume group (30–51 beds), 17.7% in the medium and 15.7% in the high-volume facility group (>101 beds).	↓ High NH volume
McConnel et al. ²⁷	76,016	≥85 = 39–56 % F 70–76%	Average rate of decline in Rs ≥1 year = 1 point/year out of 20 Mild cognitive impairment Rs reported an initial improvement followed by slow increase; moderate severe cognition Rs, reported linear increased dependency while severe cognitive impaired Rs reported an initial improvement followed by stability	↑ Moderate severe cognitive impairment
McConnell et al. ¹¹	71,388	85–94 =45.3% F 73.3%	Average rate decline = 0.07 (± 0.05) points/month out of 20, on average of 0.84 ADL points/year. Rs with no cognitive impairment and with severe differed by only -0.02 point/month. Those with no cognitive impairment would be expected decline 0.24 points/year, less rapidly. Those with severe impairment are expected to decline 0.84 ADL points/year	↑ Severe cognitive impairment
Phillips et al. ³⁶	36,584	75–84 =35.4% F 66.1%	Baseline score = average 14.9 out of 28 (±8.2); after 3 months -0.13 (p .01)	↑ Cognitive impairment, high mortality risk, female, African-American Rs
Phillips et al. ¹⁹	77,337	≥ 85 = 49% F 73%	Baseline = From 24.3% to 33.2% of Rs declined at the follow-up in transferring ability; from 27.3% to 41.5% in toileting; from 22.2% to 34.6 in eating; from 26.1% to 33.8% in walking, from 19.9 to 32.2% in bowel continence and from 23.6 to 36.3% in urinary continence	= Different settings
Sloane et al. ²⁸	1,252/693	A 84 F 76.2–78.1%	Baseline = average 11.9 out of 28 (±8.2) for NHs Rs and 7.6 (±7.9) for AL Rs NH Rs with mild dementia increased by 5.80 points/year while AL Rs 4.29 (p .059); NH Rs with moderate/severe dementia increased by 1.13 while in AL Rs .87 (p .807). While the increased decline was homogeneous in NHs specialised units and not (3.0 vs. 3.19, p .886) in AL, the increasing was respectively 5.64 and 2.91 (p .029)	↓ Moderate/severe dementia and living in ALs = NH specialised units
Wang et al. ⁴⁴	4,942	A 84 F 69%	High cognitive group = baseline average total scores 12.4 (±7.1) out of 28; after 6 months 11.5 (±8.0) (p <.001). Totally dependent increased from 0.2% to 1.4% Low cognitive group = baseline 16.5 out of 28 (±7.1); after 6 months 16.4 (±7.4) (p.45). Totally dependent increased from 4.1 to 4.6%	↑ Bladder incontinence in high and low cognitive group; balance dysfunction in high cognitive group = NHs on low cognitive group
Wang et al. ⁴³	4,942	A 84.3 F 69.3%	Baseline = 1.7% of Rs were dependent; after 6 months 2.6%. Personal hygiene baseline vs follow-up: 11.8% vs 15.5% score 0; 11.6% vs 14.8% score 4 (p<0.001). Toilet use baseline vs follow-up: 15.5% vs 21.8% score 0, 11.4% vs. 13.6% score 4 (p<0.001). Eating baseline vs follow-up: 61.1% vs 58.0% score 0, 3.3% vs 5.0% score 4 (p<0.001)	↑ Bowel/bladder incontinence and balance dysfunction = Pain and depression

Table 1i2
(Condt.)

Author(s)	Baseline/ follow-up	Age Gender	ADL Trajectory	Individual/facility-level variables
Calijouw et al. ³¹	890/564	M 84 F 75.7%	Baseline = CDS median score 44 out of 75 (IQR 30–56); after 6 months 39 (IQR 27–53); after 12 months 37.5 (IQR 27–51). 467 Rs (65.6%) remained stable, 176 (24.6%) deteriorated and 71 (9.9%) improved Baseline eating/drinking = average 3.3 out of 5 (± 1.4); after 6 months 3.0 (± 1.4); after 12 months 2.9 (± 1.4); Continence 2.4 (± 1.6), 2.1 (± 1.5) and 2.0 (± 1.5) respectively; Dressing 2.0 (± 1.3), 1.8 (± 1.3), and 1.8 (± 1.3); Hygiene 1.8 (± 1.3), 1.6 (± 1.0) and 1.6 (± 1.0)	↑ Gender, age, baseline CDS scores, cancer, urine incontinence, dementia
Dijkstra et al. ⁴⁰	68	A 82.6 F 100%	Baseline = 36.6 out of 75 (± 17.5); follow-up 25.7 (± 13.1); average impairment of -11.3 (± 10.7) ($p < .05$). A significant increased dependency was reported in eating and drinking (- 0.73; ± 1.02), incontinence (- 0.94; ± 1.23), dressing (- 0.68; ± 1.04), and hygiene (- 0.75; ± 0.95). Mobility was stable (0.15; ± 1.00 , p n.s.)	↑ Loss of social relationship, loss in the ability to communicate, care dependency at baseline
Frytak et al. ⁴²	1,215/776	NR NR	Baseline = NFs Rs average 57.0 out of 100; after 6 months 61.8, after 1 year 65.9 Baseline = ALFs Rs average 16.8 out of 100; after 6 months 20.2, after 1 year 24.9. ADLs scores increased by four points on average every 6 months	= Being in ALs or in NHs was not significantly associated to the individual ADL growth rate
Stark et al. ⁴¹	1,032/813	NR	Baseline = score average 3,721 out of 5,431 (± 1.322); after 12 months 245 (30%) of Rs worsened their functional ability, 286 (35%) reported no changes, 282 (35%) improved independence	↑ Age, baseline behaviour, baseline ADL and hospital admission
Gillen et al. ²⁶	5,518/5,518	A 79.4 F 66.1%	For each 30-day period in the initial quarter after admission, more than 3/4 of Rs manifested no functional change. For Rs at ADL-1 at the beginning of the 1 st 30 days, there was an 89% probability of remaining at that state, 94% in the 2 nd 30-day period and 97% during the 3 rd 30-day period	↑ Gender, age, orientation status, dementia
Helvik et al. ³⁹	932/160	A 84.5 F 73.6%	Baseline = average 18.8 out of 30 (± 5.3); after 12 months 19.6 (± 5.2); after 31 months 20.8 (± 4.8); after 51 months 21.6 (± 4.6). The rate of ADL decline flattened during the follow-up	↑ Severe dementia, comorbidity, agitation, apathy and no use of anxiolytic and ant dementia medication
Ouslander et al. ³⁴	430/178	A 82 F 77%	Baseline prevalence of daytime UI = 39%; after 2 months incidence 27%; after 1 year, incidence 19%. The continence status of about two-thirds of Rs remaining in the NH was stable after 1 year: 22% had daytime UI, and 42% were continent	↑ Male, dementia, faecal incontinence and the inability to ambulate/transfer
Porell et al. ⁴⁵	59,407	A 85 M.195 (± 0.40)	Baseline = average ADLs 3.76 out of 5; quarterly follow-up = the impairment mean increased around 0.06 ADL	= Weak association between ADL decline and structural attributes of NHs
Rudman et al. ¹³	3,450	65–79 = 57.6% F 0–11.8%	Follow-up after 6 months = average loss in eating 13.7% (± 7.7); mobility 22.6% (± 14.3); toileting 17.3% (± 10.0); transferring 16.0% (± 10.4)	↑ Smaller NH size, slower Rs turnover rate, lower ratio of SSr to LSr at the NH level
Slaughter et al. ⁶	120/114	A 86 F 78%	After 1 year = 48 Rs (out of 114, 42.8%) experienced disability in walking; incidence in walking disability was 40.8% (95% CI 32.7–50.2) and around 27% (95% CI 19.7–36.5) was excess disability	↑ More advanced dementia, comorbidities and less supportive facility environments
Slaughter et al. ³⁵	120/114	A 86 F 78%	After 1 year = 49 Rs (out of 114, 51.7%) experienced disability in eating; incidence was 40.8% (95% CI 32.7–50.2%) and around 23.6% (95% CI 16.6–33.0%) was excess disability	
Sutcliffe et al. ¹⁴	308/168	A 82.8 F 68.8%	Baseline = on average 12.2 out of 20 (± 5.2); after 5 months 12.5 (± 5.4); after 9 months 11.8 (± 5.9) Only 12% in the low dependency group moved into a higher dependency group, demonstrating stability in dependency in the first 9 months of care.	↑ Cognitive impairment
Walk et al. ⁷	2,527	A 81.6 F 73.6%	After 30 months = increased dependence in bathing (+ 20.9%), bladder continence (+ 11%), and mobility (+ 10.1%) ($p < 0.001$). Eating dependence was nearly unchanged (-2.3%). A total of 8% of Rs dependent in bathing at the assessment were not dependent at the follow-up; 52.0% for eating, 34.1% for bladder continence and 30.3% for mobility	↓ SSSs, Gender, facility quality of care
Yeh et al. ⁴⁶	1,125	A 83.1 F 0%	After 12 months = 65 (5.8%) Rs declined functionally	↑ Parkinson disease, baseline RAP of cognitive loss, mood problems, and increased RAP triggers

AL, ALFs = Assisted Living facilities, NHs = Nursing Homes; RAP = Resident Assessment Protocol Rs = Residents; LSs = Long Stayers; SSSs = Short Stayers; UI = Urinary Infections;
Participants at Baseline/Follow-up = number of Rs included in the study at the baseline/number of Rs included in the last follow-up. When Rs were the same, those included at baseline was reported

A = Age Average

M = Age Median; % prevalent group among different age groups

F = Female %

↑ = Functional decline predictor factors, ↓ = Functional decline protective factors, = Not significantly associated/correlated to functional decline

Supplementary Table 1

Criteria adopted to evaluate the quality of the studies included (modified from²⁵)

- 1) Is the aim of the study consistent with the aim of the systematic review (SR)? (yes 1; no 0)
- 2) Is the study design declared and consistent with the aim of the SR? (yes 1; no 0)
- 3) Is the definition of functional dependence (or in the specific ADL studied) consistent with the aims of the SR? (yes 1; no 0)
- 4) Were the ADL measures under consideration well described? (yes 1; no 0)
- 5) Was the target population defined in terms of space (context), timing (year at the baseline and follow-up), and main demographic characteristics (e.g. age, gender)? (yes 1; no 0)
- 6) Was the follow-up duration established? (yes 1; no 0)
- 7) Was the follow-up rate 70% or more of the participants at baseline? (yes 1; no 0; not applicable 1)
- 8) Were the reason(s) for drop-out declared? (yes 1; no 0; not applicable 1)
- 9) Were drop-outs comparable with follow-up participants? (yes 1; no 0; not applicable 1)
- 10) Was the validity/reliability of the measure assessing ADL reported? (yes 1; no 0)
- 11) Were confounders accounted for in the analyses? (yes 1; no 0; not applicable 1)
- 12) Did authors assess, control and/or acknowledge among the study limitations any potential bias? (yes 1; no 0)
- 13) Was the data analysis described appropriately? (yes 1; no 0)
- 14) Were findings presented in an appropriate manner? (yes 1; no 0)
- 15) Were the conclusions consistent with the findings? (yes 1; no 0)

Number of 'yes' * 1 + number of 'not applicable' * 1 = total possible sum (from 0 to maximum 15)