

**Specialized vs. Integrated Care of People With Dementia**

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## **Specialized vs. Integrated Care of those with Dementia**

### **Executive Summary:**

**Question:** Do people with dementia residing in dementia-specific care facilities experience more positive outcomes in comparison to those with dementia who are integrated into a traditional care facility?

**Method:** A systematic review was conducted. Initial literature search in EBSCO and PubMed yielded 333 articles. Key search terms included “dementia OR Alzheimer Disease”, “functional decline”, “assessment”, and “special care unit”. Included were all primary research studies that used SCU residents as the study group and non-SCU residents as the control group. Any clinical outcome that was measured and compared was included in this review. I considered it to be imperative to have a control group of a similar cohort at a similar stage in the disease process as a direct comparison to the intervention group in order to justify a conclusion that would indicate that one type of care was determined to be better than another. I included all studies involving those with a diagnosis of dementia and chose not to differentiate based on specific disease or type of dementia. Ten studies met the criteria and were included in this review.

**Findings:** Five studies had negative and the remaining five had mixed results giving strong indication from the literature that the SCU environment does not contribute to overall better outcomes for the person with dementia. One additional study that was published after the initial literature search confirmed this conclusion. Currently research does not generally support better clinical, behavioural, functional or cognitive outcomes for those with dementia residing in a SCU in direct comparison to those with dementia residing in a traditional integrated facility.

**Recommendations:** I recommend returning to the current body of research to seek out a variety of research methods and study designs in order to formulate a general consensus as to the value of the SCU to those with dementia. Looking at the complete body of research on this topic could point to areas that may be of more significance and give greater clarity as to why SCU’s have developed so rapidly and continue to proliferate as a care option for those with dementia. The opinion of informal and formal caregivers, Seniors’ groups, the Alzheimer Society, and others advocating for the rights of those with dementia must be explored to greater depth to determine not just what options they prefer, but why they are preferred. Further study is required to identify the factors that best determine quality of life for those with dementia. As well, the best method for obtaining this information needs to be explored and developed. Due to the fact that each individual is affected differently, having a range of care options will enhance the ability of finding a suitable option that will meet the needs of the person with dementia and their families. In light of the fact that up to 70% of those within traditional care environments have some form of cognitive impairment (Calkins, 2001; Maslow & Ory, 2001), it is imperative that the staff in all types of care facilities are educated to provide compassionate and competent care to those with dementia.

# Specialized vs. Integrated Care of those with Dementia

## 1. Abstract:

Special Care Units or “SCU’s” have been in existence for well over two decades (Maslow & Ory, 2001). The purpose of this systematic review is to determine if existing literature identifies more positive outcomes for those with dementia who reside in a dementia-specific care facility (SCU) in direct comparison to those with dementia who are integrated into a regular or traditional care facility. Through EBSCO and PubMed, 10 primary research articles directly comparing outcomes of those with dementia in each of the two environments were obtained for review. Current research does not support the SCU as being a care environment that results in more positive outcomes for those with dementia.

## 2. Question:

Do people with dementia residing in dementia-specific care facilities experience more positive outcomes in comparison to those with dementia who are integrated into a traditional care facility?

## 3. Context:

### *Purpose*

The purpose of this systematic review is to determine if existing literature identifies more positive outcomes for those with dementia who reside in a dementia-specific care facility in direct comparison to those with dementia who are integrated into a regular or traditional care facility. This will inform Chinook Health as they make long range plans to meet the growing need of supportive living options for those with dementia who are no longer able to remain in their own home due to higher care needs, lack of family/community support, or safety concerns. This will also assist in the development of admission criteria to current facilities.

### *Canadian Context*

It is currently estimated that 435,000 Canadians over the age of 65 have Alzheimer’s Disease or a related dementia. In 2006 there will be an estimated 97,000 new cases of dementia diagnosed. In 2011, the year the baby boomers start turning 65, new cases of dementia are expected to reach 111,560/year. By the year 2031, over three quarter of a million Canadians are expected to have Alzheimer’s Disease or a related dementia. Approximately half of those with dementia reside in an institutional setting (Alzheimer Society of Canada, 2006)

Dementia-care facilities, consistently referred to in the literature as Special Care Units or “SCU’s”, have been in existence for well over two decades; however, it was not until the late 1980’s that strong claims about their effectiveness were being made by clinicians and consultants who were sure that this was the answer to improving

institutional care for those with dementia (Maslow & Ory, 2001). Due to the growing numbers of people with dementia who will require care, understanding the current research is imperative in order to plan for the future needs of Canadians who suffer from this chronic progressive neurological disorder.

### ***Chinook Health Context***

In 2002, the percentage of those over the age of 65 residing in Chinook Health was 13.3%, higher than both the provincial average of 10% and the national average of 12% (Alberta Government, 2002). Although there are new medications now available to slow the progression of Alzheimer disease and other forms of dementia, a cure is yet to be found and at the present time we must acknowledge that a growing elderly population will result in an increased prevalence of dementia within our population. Long range planning needs to account for the increasing number of those with dementia who will require care.

Chinook Health values independence, autonomy, and self-care, and currently holds the belief that integrating those with dementia (assessed to have no risk of elopement) into a “regular” environment will be beneficial in maintaining their functional and cognitive status for a longer period of time as their disease progresses. It is currently unknown whether integrating those with dementia into a regular or traditional environment is beneficial in maintaining their functional and cognitive status. It is assumed that better functional and cognitive outcomes would result in greater independence and a higher quality of life for those who suffer from dementia. Identifying if better outcomes are achieved by admission into a SCU compared to those in traditional care will help to inform the health region on whether or not their current values and subsequent long range planning are congruent with best practice as identified in current research findings.

## **4. Literature Identification & Selection:**

### ***Identification***

Literature identification was completed in October, 2005. Through EBSCO, an advanced search was conducted in the following data bases:

- Nursing & Allied Health Collection: Comprehensive
- Psychology and Behavioural Sciences Collection
- CINAHL Plus with Full Text

Search terms included the following key words:

- Dementia OR Alzheimer Disease AND Functional Decline AND Assessment
- Dementia OR Alzheimer Disease AND Special Care Unit

Both searches were repeated in PubMed to yield a total of 333 articles.

## *Selection*

Titles and abstracts were reviewed on all 333 articles. Non-English sources were excluded. Duplicate articles were also eliminated. Included were all primary research studies that used SCU residents as the study group and non-SCU residents as the control group to measure and compare outcomes of people with dementia living in these two different care settings.

In order to draw a conclusion that indicates one care setting offers a better quality of life than another based on more positive outcomes, I chose to look at only those studies that involved a direct comparison between the residents with dementia living in each of these two environments. As a result, I did not include studies that measured family or staff satisfaction with the SCU setting, studies that measured change of individuals within a single environment over time, or studies that focused on measuring the quality of the environment itself rather than the residents within. My goal was to draw a general conclusion based on measured outcomes included in the current body of research.

Any clinical outcome that was measured and compared was included in this review except for wandering as the goal of most SCU's is to allow for unrestricted wandering, which currently is assumed to be more positive for the client with dementia. Including all outcomes measured gives a general picture of where the greatest good can be accomplished. Clinical outcomes that demonstrate a benefit to clients of the health care system are often the measure and justification for allocation of resources. Administrators are under constant pressure to incorporate evidence based research into practice while ensuring fiscal responsibility. SCU's in general have higher capital and operating costs than a regular or traditional environment. Older facilities often require extensive remodeling or renovations to add a SCU. New purpose-built facilities may incur added cost from use of specific technology and environmental design to enhance monitoring and safety. Enhanced staffing levels, ongoing staff education and special client programming add to the cost of operating a SCU. In order to justify a higher cost, administrators need to know where the greatest benefit lies.

I chose to include all outcomes that had been measured in the research to get a broad overview in order to draw a general conclusion regarding the benefit to the dementia clients' quality of life. Research that supports better outcomes such as cognition and ADL function that is preserved or enhanced; less anxiety, agitation and aggression; increased social interaction; less resistance to care and use of physical or chemical restraints; lower infection and hospitalization rates; all combine to give a picture of a better quality of life for those with this chronic debilitating disease who are not able to overtly state their preference for one type of facility over another. It is my assumption that clients who are experiencing a higher quality of life with fewer altered behaviours will also result in more satisfied staff which will enhance recruitment and retention in a growing field where worker shortage is of real concern.

I am also assuming that quality of life for clients will enhance family/informal caregiver satisfaction resulting in positive public perception for this care option.

I considered it to be imperative to have a control group of a similar cohort at a similar stage in the disease process as a direct comparison to the intervention group in order to justify a conclusion that would indicate that one type of care was determined to be better than another. It was evident that there was not enough research to focus in on one specific diagnosis or age group. Although there is research proving or disproving the benefit of specific elements of a SCU, I was looking for a generalized conclusion of whether or not it can be said with any certainty that SCU's result in better outcomes and thus a better quality of life for those with dementia. Because of this general approach, I included all studies where there was any direct comparison made between residents in the two different environments.

I included all studies involving those with a diagnosis of dementia and chose not to differentiate based on specific disease or type of dementia. Diagnosis begins with evaluating symptoms and ruling out other conditions, and is considered to be "possible" or "probable" for a specific type of dementia. Dementia usually has an insidious onset, and a definitive diagnosis of a specific type of dementia is often possible only upon autopsy (Fisher Center for Alzheimer's Research Foundation, 2006). Although Alzheimer disease is the most prevalent form of dementia, current research into various types of dementia has lead scientists to believe that some may have been misdiagnosed with Alzheimer disease, when actually they have a different type of dementia (American Academy of Neurology, 2005). Due to the challenge with diagnosis and because many individuals will have mixed types of dementia, I did not base study inclusion criteria on a specific disease or type. This also reflects the fact that admission is usually based on the general criteria of having some form of dementia and not on a specific diagnosis.

Of the 333 articles reviewed, eleven met the criteria for inclusion. One article was a doctoral dissertation that was inaccessible resulting in a total of ten articles for this systematic review.

## **5. Data Extraction and Summary:**

### ***Study Characteristics***

Studies dated from 1990 to 2004. Six studies involved multiple sites and in some cases multiple cities, regions, or states. Four were conducted at a single site or facility. Larger studies incorporating more sites and clients are considered to be more reliable than small, single site studies. Due to the fact that the study participants were not randomized, larger cohorts would help to diminish bias by increasing the chance that both the known and the unknown determinants of the outcome would be more equal (User's Guide, 2002)

There are no pure randomized control trials identified in the literature, although one attempt was made to randomize admission of those with dementia into a SCU or a traditional facility. In this case the study failed to maintain randomization of participants throughout the length of the study. One large multi site study did randomize facility selection and within facilities selected a random sample of the residents for the study. Due to ethical and financial considerations, randomization of clients prior to admission is not a feasible method particularly in private facilities where people are paying based on their choice of care facility. Choice is often based on location, reputation and services that are provided. Again, larger studies would help to decrease the effects of confounding factors.

Six studies were prospective or prevalent studies of a cohort, matched group, or case control design. Two were a retrospective review of medical records comparing matched cohorts, and one studied matched groups at a single point in time. One study was a non-equivalent experimental pretest/posttest design that replaced initial cohort members who were lost to attrition (largely due to death). In the absence of RCT's I had to rely on cohort or case-control studies which subsequently are considered to be the strongest evidence available, while recognizing that the causal relation between the intervention and the outcome is much weaker than evidence from RCT's (User's Guide, 2002).

Cohort studies are considered appropriate for this type of research as long as the cohorts are matched equally. Eight of the ten studies had set dementia criteria for study inclusion based on meeting medical diagnostic criteria or validated cognitive screening exams. The remaining two studies did not specify their criteria for admission into the study, although one indicated it did have specific criteria, and the other relied on admission criteria to the SCU as their criteria for study participation.

Although most studies identified some combination of age, gender, race, education level, previous occupation, length of stay in facility, baseline function in cognition and ADL function for comparison of the experimental and the control groups, only one study identified co-morbidities, and no study accounted for the effects of other diseases or treatments on outcomes.

There is little evidence in the literature to support drawing conclusions regarding facility based care options for those with milder cognitive deficits. It is assumed that the majority of this group remain at home in the community and do not seek facility care until disease progression results in care or safety issues. In general, all ten studies involved those with moderate to severe dementia.

### ***SCU Characteristics***

Eight studies were conducted in the USA and the remaining two were of Canadian origin. There is no standard definition of what a Special Care Unit is, or government legislation for the specific type of service or care standard it is required to provide in either country.

Seven studies were conducted in Long Term Care facilities in which the SCU would need to meet the same standards of care as those of the traditional care facilities which are highly regulated by the government in both the USA and Canada. Two studies did not specify facility designation although it is assumed that they were associated with traditional Long Term Care. One study included Assisted Living facilities in the control group. Currently, Assisted Living is a highly unregulated industry with private facilities having no government regulations for care standards in place.

Although generally SCU's are a smaller, separate unit with room for wandering, often with locked doors to prevent elopement, there are many other features of a SCU for which there are no standards. Although indicated by some, I was unable to ascertain the following information about all the SCU's in these studies:

- unit size and layout
- locked doors
- access to secured outdoor environment
- private or shared rooms
- purpose built or adapted environment
- specialized activity programming
- admission and discharge criteria
- length of time in the facility
- specialized staff training and support
- staff ratio of professional and non-professional staff
- management and staff characteristics
- specific design features such as lighting, use of colour, type of flooring etc.
- private vs. publicly funded

Because these things were not specified, it is more challenging to draw a general conclusion as different care facilities could yield very different results based on the type of facility and range of services it provides to its clients. The above list of variables may or may not have a direct impact the outcomes measured and thus confound the results.

***Study Outcomes Measured:***

Measurements were completed using research validated tools, direct observation, staff and family interview, and review of medical records. In most of the ten studies, a variety of measures were completed and multiple outcomes were evaluated. The table on the following page contains a summary of the data:

Author & Year	Type & Length of Study	#Sites & Size E=Experimental group C=Control group	Outcomes Measured	Positive or Negative Outcomes Comparing those in SCU to those in Traditional/Regular facilities
Coleman et al. 1990	-Retrospective Cohort -1 year	Single site E = 47 C = 36	-Hospitalization -Cognition	<u>Negative:</u> -Higher hospitalization rate -Greater decline in cognition
Leon & Ory 1999	-Prospective Cohort -1 ½ years	Multi site E=432 C=164	-Aggression	<u>Negative:</u> -SCU does not decrease aggression
Liu et al. 2000	-Prevalent Cohort -1 ½ years	Multi site E=176 C=403	-Cognition -ADL function	<u>Negative:</u> -Greater decline in cognition -Greater functional decline
Morgan et al. 2004	-Matched Cohort -Point in time	Multi site E=92 C=92	-Cognition -Resistance to care -Restraint use	<u>Negative:</u> -Significantly lower cognitive status -Greater resistance to care <u>Positive:</u> -Less restraint us
Perls & Herget 1997	-Retrospective Case Control -4 years	Single site E=41 C=123	-Infection rates	<u>Negative:</u> -Higher upper respiratory infection rate
Phillips et al. 1997	-Prospective Cohort -1 year	Multi site E=1228 C=76109	-ADL function -Continence -Weight loss	<u>Negative:</u> -No difference in ADL function, Continence or weight loss between SCU and non-SCU
Reimer et al. 2004	-Prospective Matched Group -1 year	Multi site E=62 C=123	-Cognition -Anxiety/Fear -Interaction within the environment -Agitation -Social activity	<u>Negative:</u> -More agitation -No difference in social activity <u>Positive:</u> -Cognition slightly better -Less anxiety/fear -More interaction within the environment
Saxton et al. 1998	-Prospective Matched Group -1 ½ years	Single site E=26 C=19	-Mobility -Cognition -ADL function	<u>Negative:</u> -no difference in cognition or ADL function <u>Positive:</u> -Less decline in mobility
Swanson et al. 1994	-Non-equivalent Quasi-experimental design -1 year	Single site E=13 C=9	-Catastrophic Reactions -Social interaction -ADL function -Cognition	<u>Negative:</u> -no difference in cognition or ADL function <u>Positive:</u> -Decreased catastrophic reactions -Increased social interaction
Volicer et al. 1994	Prospective Cohort -2 years	Multi site E=113 C=50	-Level of discomfort -Hospitalization -Mortality rate	<u>Negative:</u> -Higher mortality rate <u>Positive:</u> -Less discomfort -Lower hospitalization rate

## 6. Findings and Analysis:

Five studies had negative and the remaining five had mixed results giving strong indication from the literature that the SCU environment does not contribute to overall better outcomes for the person with dementia. Of particular note is the fact that other than one study showing a slight difference, no studies gave any indication that the cognitive or functional status of those with dementia can be maintained or improved in this environment. The fact that each of the ten studies had negative or at best mixed results deserves further investigation and evaluation. This result is counter-intuitive and in direct opposition to the movement within our health care systems to build and develop more SCU environments.

Recognizing that only two of the ten studies were conducted in the previous five years, and feeling that with the advances in knowledge of dementia care and environmental impact that perhaps more recent research would yield more positive results, I searched again in EBSCO. I was able to find one more study that met my criteria but was published in December 2005, after my initial data collection date.

This study compares outcomes for those residing in “innovative Alzheimer’s special units utilizing social models of care rather than medical models” (Aud et al., 2005). These SCU’s, unlike most of those in the previous studies, identified that they were purpose-built, specially designed environments that complied with increased staff ratios and staff training requirements. These units were small home-like environments with private rooms, indoor and outdoor activity spaces, and were “designed and utilized in such a way as to reflect the individual preferences of residents and to provide as much independence and opportunities for choices throughout the day as possible” (Aud et al., 2005). This study was also of interest because it used the MDS 2.0 for data collection on admission, quarterly and with any significant change in condition, which is the same tool currently being used in Chinook Health Continuing Care facilities. Their hypothesis was that SCU residents would show fewer signs of agitation, anxiety, aggression, and depression; have fewer falls; use fewer psychoactive medications; and have less weight loss than residents in non-dementia specific nursing home settings. Contrary to what was expected, none of the hypothesis were supported by the MDS data.

Author & Year	Type & Length of Study	#Sites & Size E=Experimental group C=Control group	Outcomes Measured	Positive or Negative Outcomes Comparing those in SCU to those in Traditional/Regular facilities
Aud et al. 2005	-Multi-method comparative study using aggregated MDS data collected on each resident at admission and quarterly through duration of stay	Multi site E = 88 C = 4456	-Agitation -Anxiety -Aggression -Depression -#Falls -Use of psychoactive medication -Weight loss	<u>Negative:</u> -Higher percentage of agitation, anxiety, aggression, depression -Increased # falls -Increased use of psychoactive medication -Similar degree of weight loss

Being dissatisfied with the results of this systematic review based on my own personal observation of dementia special care units, I went back to the literature to seek additional background information on the history of the rapid addition and development of SCU's. Two articles published in *Alzheimer's Care Quarterly* (Maslow & Ory, 2001; Calkins, 2001) explore the advances made during the preceding decade in research and understanding of the environmental impact on the care of those with dementia, and the evolution of SCU's. According to Maslow and Ory (2001), in the early 1990's there was no research that could demonstrate that special care units, or any particular components of them were more effective than non-specialized nursing home units for people with dementia. Throughout the 1990's as SCU's and dementia-specific programming increased exponentially, the evidence was still not as great as expected in demonstrating the positive impact of the SCU for those with dementia; however, other key findings have been demonstrated:

- Although there is now more understanding and a general consensus of what a SCU unit is, there is no uniform national standardized definition for facilities that call themselves a special care unit making research challenging with the uneven playing field (Maslow & Ory, 2001).
- Families generally tend to express higher satisfaction with care when their loved one is in a SCU compared to those in non-SCU's (Maslow & Ory, 2001).
- The most demonstrable benefits of SCU may be for those cognitively intact residents who are segregated from residents with dementia (Maslow & Ory, 2001).
- There are many isolated factors that are associated with positive resident outcomes from administration practices and staff stability to smaller scale environmental conditions such as lighting levels, size of facility, "home-like" setting, and noise levels (Calkins, 2001).
- Up to 70% of all nursing home residents have some form of dementia, but only a small proportion of those reside in a SCU (Calkins, 2001; Maslow & Ory, 2001).

Although research has yet to prove the benefits of the SCU to the dementia population, due to the "uneven playing field" it is not appropriate to apply these results to individual SCU's. Until the SCU has a consistent definition, and the care and services provided are standardized, any direct comparison cannot be considered completely valid. And yet, the fact that all ten studies included negative results cannot be ignored altogether. As I reflect upon this overwhelming evidence, I am left asking if this study design is the most appropriate way to determine whether the SCU offers better outcomes and thus a better quality of life for those with dementia.

The fact that families tend to be more satisfied with this care setting warrants further exploration. What do families perceive and experience that is not reflected in the quantifiable outcome measures of these particular studies? Does the family of a person with dementia measure quality of life in ways that cannot be confirmed through quantitative research methods? Further study using a qualitative design with family and informal support would help to inform on what is considered to be a

“better” environment for those with dementia. Studies involving front-line staff, administrators, and expert clinicians may also add to the body of knowledge that seeks to define quality of life for those with dementia.

Although in health care we like to believe that we are responding to the needs of individuals, we often resort to the principle of utilitarianism which leads us to make choices that generate the greatest good for the greatest number of people. In considering how to manage the care needs of those with moderate to severe dementia within a population, we cannot ignore the benefit of segregation to the other residents within a facility. The deterioration in health status that often leads to institutionalization results in significant loss to the individual which may include loss of physical function, decline in cognition affecting memory and coping skills, loss of property and possessions as people must leave their homes to enter a care facility, and a loss of independence and autonomy requiring a reliance on others to meet their needs with limited resources to address their wants. Compounding these losses with invasion of privacy from a wandering dementia resident or added stress due to living with people expressing altered behaviours is a significant factor to consider when addressing placement issues.

It is interesting to note that many factors studied in isolation have proven to benefit those with dementia. Perhaps finding the right combination will yield different study results, or perhaps Alzheimer disease and other related dementia’s affect each person so individually, that there will never be a “one-size-fits-all” solution.

## **7. Recommendations**

Currently there is no evidence in the literature that SCU’s are a better option to care for those with dementia. Research does not generally support better clinical, behavioural, functional or cognitive outcomes for those with dementia residing in a SCU in direct comparison to those with dementia residing in a traditional integrated facility. This is congruent with the values of Chinook Health which believe in integrating those with dementia (assessed to have no risk of elopement) into a “regular” environment.

In light of these findings, I would recommend returning to the current body of research to seek out a variety of research methods and study designs in order to formulate a general consensus as to the value of the SCU to those with dementia. Looking at the complete body of research on this topic could point to areas that may be of more significance and give greater clarity as to why SCU’s have developed so rapidly and continue to proliferate as a care option for those with dementia. Further study into the perspective of families and informal caregivers is required as these are the key stakeholders who are influencing the decisions of RHA’s and government. The opinion of informal and formal caregivers, Seniors’ groups, the Alzheimer Society, and others advocating for the rights of those with dementia must be explored to greater depth to determine not just what options they prefer, but why they are preferred.

Perhaps my assumption that better clinical outcomes directly correlate to a better quality of life is false for this population. Further study is required to identify the factors that best determine quality of life for those with dementia. As well, the best methods for obtaining this information need to be explored and developed. Further study is needed to determine what exactly should be considered a better outcome for those with a chronic progressive neurological disorder. “In the setting of progressive dementia, it is perhaps unreasonable to expect environmental modification to slow loss of cognitive function or functional decline to a clinically significant degree” (Albert, 2004).

An avenue of research that may give a different picture would be to compare cohorts of individuals to themselves as they move through different care environments. Controlling for all confounding factors between different cohorts (age, level of education, co-morbidities, marital status/informal support, etc.) was not accounted for in all ten studies, however measuring the same person in different environments may control for some of these differences, and help to eliminate some of the bias.

For health care systems I would recommend continuing to provide segregated care facilities incorporating those individual factors which have been proven to be of benefit to those with dementia. In setting admission criteria, focusing on those with altered behaviours or severe cognitive impairment is recommended as the benefits to family, staff, and cognitively well residents has been reported in the literature. Due to the fact that each individual is affected differently, having a range of care options will enhance the ability of finding a suitable option that will meet the needs of the person with dementia and their families.

At this time, research does not give any indication of benefit or harm to the individual with mild or early stage dementia from being integrated into a regular environment. Again, a range of options that offers different types of environments and different levels of support and services would enhance caregiver’s ability to choose the most appropriate care setting.

In light of the fact that up to 70% of those within traditional care environments have some form of cognitive impairment (Calkins, 2001; Maslow & Ory, 2001), it is imperative that the staff in all types of care facilities are educated to provide compassionate and competent care to this vulnerable group of people in order to maintain their dignity in the face of this devastating disease process.

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