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The Home is the Hub of Health in Very Old Age: Findings from the ENABLE-AGE Project

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Abstract

The aim was to explore health in relation to the home as experienced by very old, single-living Swedish people. Applying a grounded theory approach, 40 men and women aged 80–89 were interviewed in their own homes. Data analysis revealed the main theme “The home is the hub of health”, comprising two categories, “The home as support for health”, and “Having an inner driving force to maintain health”. Health was described as being active and participating, and during the aging process the home became an increasingly important source of support. The older people were aware of their vulnerability, and knew that their life situation could change rapidly. Thus, health was always interpreted in relation to this. They had a strong inner driving force to maintain health, and within the home they challenged their capacity, and used different adaptive strategies targeting person-environment-activity transactions. Our findings imply the need for focusing on the opportunities for activity and participation in all interventions. They also challenge current national and international housing policy emphasizing the benefits of staying put, thus contributing to a more diverse view of what kind of housing arrangements are optimal for very old people.

Keywords: Elderly, semi-structured interviews, daily activities, societal participation, adaptive strategies.

1. Introduction

Worldwide, the population of very old people (80 years and above) is rapidly increasing. In the Western world, an increasing proportion of very old people remain living in their ordinary homes despite health decline. While current health and social policy aims to support “aging-in-place”, if aging is to be a positive experience for older people then measures to help them remain healthy and active are necessary. In particular, home environments that support health is needed (World Health Organization, 2002). As people grow older they spend relatively more time in their homes; very old people tend to spend on average 80% of their time at home. Consequently, in very old age daily activities are predominantly performed in the home and its close surroundings (Baltes, et al., 1999). This poses considerable challenges to community planning and housing development (Gitlin, 2003), however, housing issues are rarely considered in national and international social policy frameworks. In fact, the home is an under-researched factor with respect to its role in maintaining and improving health among older people, and more research is needed to provide an evidence base for housing policy and recommendations.

Previous research on the role of the home for older people revealed that it is the most important locus in their lives. For example, the home means safety and security for the person who lives there (Dahlin-Ivanoff et al., 2007), and it is an important signification of independence and autonomy in very old age (Haak et al., 2007b). Moreover, participation in valued activities, as well as the ability to make autonomous decisions in daily life, is to a large extent related to a supportive home (Haak et al., 2007a; Haak et al., 2007b).

Furthermore, relationships between different aspects of housing, for example accessibility, usability and the meaning of home on the one hand, and independence in daily activities and perceived health on the other have been found (Iwarsson et al., 2007; Oswald et al., 2007).

This is a strong indication of the supportive role of the home environment in very old age, in particular due to the fact that older people are increasingly vulnerable to environmental demands (Iwarsson, 2005). While “aging-in-place” in one’s own home is seen to positively enhance well-being, autonomy and participation among older people (American Association of Retired Persons, 2000; Perez et al., 2001; Rosel, 2003; Mynatt et al, 2004), the evidence of links between the home and health of older people is limited (Spillman, 2004; Gitlin et al., 2006). In particular, in order to refine the ongoing debate about which type of housing arrangements, in very wide sense, supports health among older people, qualitative studies investigating relationships are necessary (Iwarsson et al., 2007). However, no research has focused on how the very old people themselves perceive the relations between home and health. Accordingly, the aim of this study was to explore health in relation to the home as experienced by very old, single-living Swedish people.

2. Materials and methods

2.1 Study context and design

Data were collected as part of the ENABLE-AGE Project, involving 1 918 very old single-living people from Sweden, Germany, the United Kingdom, Hungary, and Latvia (Iwarsson et al., 2005), in Sweden n=397. Out of those, a sub-sample of 40 participants in each country was selected for an in-depth qualitative study, the ENABLE-AGE In-Depth Study, with the purpose of revealing a deeper understanding of the meaning of home, autonomy, health and well-being, as well as participation in very old age. This study is based on interviews from the Swedish sample.

The qualitative approach of this study was based on grounded theory (Glaser and Strauss, 1967), as developed by Charmaz (2003; 2006). In view of the fact that the collected data

yielded rich and comprehensive information, this paper focuses specifically on the relationships between home and health, while other results are presented elsewhere (Dahlin-Ivanoff et al., 2007; Haak et al., 2007a; Haak et al., 2007b).

2.2 Participants

Already at the time of the survey study data collection, the participants had signaled their interest and tentative agreement to participate in the forthcoming in-depth study. For the theoretical sampling procedure the Swedish ENABLE-AGE Survey Study database was used to identify potential participants representing diversity in the following variables: gender, age, type of dwelling, self-rated perceived health, dependence in activities of daily living, aspects of person-environment fit, and degree of participation. All 40 participants (17 men and 23 women) were between 80 and 89 years of age (Md: 85 years). The majority of them lived in multi-dwelling blocks, while only a few lived in single-family houses. Twenty-one participants rated their health as very good or good, while another 19 rated it as fair or poor. Six participants were dependent in personal activities of daily living, 25 in instrumental activities of daily living, and six were dependent in both. About 50% of the participants were engaged in clubs, voluntary work or the like. There was also variation among participants when it comes to accessibility problems in their homes.

2.3. Data collection and analysis

An interview schedule was developed, based on the five key concepts of the ENABLE-AGE Project. The interviews were accomplished in an iterative process by a team of four: the two authors and two additional interviewers. Each of them performed ten interviews, successively accomplished in rounds of one to three interviews per interviewer. The time and date of the interviews were arranged over the telephone, in accordance with each participant's

preferences. All interviews were conducted at home visits, following the predetermined themes, with individually adapted follow-up questions (Charmaz, 2003). Each interview lasted 1- 1.5 hours. Immediately thereafter the interviewer took field notes. During the interview and analysis period the interviewer team met regularly once a month. At the first two meetings one interview from each interviewer was discussed, and on the three subsequent meetings two to three interviews from each interviewer were discussed. After each of these discussions the interview schedule was revised. The subsequent meetings were focused on more analysis of the transcripts and the emergent categorization of the data. After the interviews and the first step of analysis were completed, it was considered necessary to carry out separate analytical processes focusing on each of the key concepts of the ENABLE-AGE In-Depth Study (see also Dahlin-Ivanoff et al., 2007; Haak et al., 2007a; Haak et al., 2007b).

All interviews were taped and transcribed verbatim during the interview procedure and close to the interview occasion. The field notes written down immediately after the interview were in fact a first step of analysis. They were used to document the interviewer's interpretations of the context of the interview, the key points revealed in the interview in relation to the research questions, initial ideas for analytical themes, relationships between themes, and the general tone of the interview. In a first step of analysis, in order to maximize theoretical sensitivity and rigor in between rounds of interviewing, the interviewer team had regular meetings for analysis and discussion. The tapes were listened to several times, and the verbatim-typed interviews were analyzed using line by line coding followed by focused coding (Charmaz, 2003). Codes emerged, were compared and sorted into categories in order to identify the participants' experiences of the relationships between home and health. Each category was examined in order to identify the properties that characterize the category, and subcategories

emerged. The analysis was conducted in an iterative process, moving back and forth, constantly re-examining data and the emerging categories.

Before each interview written informed consent was obtained, and each interview was treated confidentially. The study was approved by the Ethics Committee, Lund University, Sweden.

3. Results

3.1 The home is the hub of health

Health was described in terms of being able to manage daily activities at home and to participate in society. During the aging process the home became increasingly important and in many different ways the center, the hub, of the lives of the very old people. It was a safe and firm place to return to for rest and recovery, and the place where one could manage on one's own terms, in spite of disease and declining functional capacity. The very old people were very aware that due to aging they belonged to a group that is vulnerable. They knew that their life situation could change rapidly, and health was always interpreted in relation to this. Still, they had a strong inner driving force to maintain health, and within the familiarity of the home they challenged their capacity and took action for maintained health. Accordingly, the home was an important source of support for health. As a result of the analyses the main theme, *The home is the hub of health*, emerged, comprising two categories: *The home as support for health*, and *Having an inner driving force to maintain health*.

3.1.1 The home as support for health

The home was a safe and familiar environment, and a place that the older people could return to when life outside home was too demanding. A familiar, safe and functional home compensated for declining capacity, supported routines developed over the years, and

enhanced daily activities and participation. Thus, the home was an important source of support for the health of the very old people. As a result of the analyses, two subcategories emerged: *The home is a familiar and safe place*, and *The home is functional*.

3.1.1.1 The home is a familiar and safe place

The home offered familiarity and security, and was the place where the very old people could be on their own without necessarily having to negotiate with anyone else. They identified themselves with their home, and thus to a large extent used the home environment as an extension of themselves. The home could on the other hand be an unfamiliar place where one felt like a stranger, for example after a forced move, and also a place where one felt insecure in the neighborhood. Being able to maintain close relationships to children and grandchildren was of the utmost importance for health. In relation to this, the very old persons imagined that living in sheltered housing would seriously affect their possibilities of receiving visits from relatives and friends. As one very old man expressed his perceptions of the home:

Home, well, I think of a place where I can be in peace and where I can invite my friends. That's probably the main thing (...). Yes, it means a great deal, I think (to be in peace) because if you have some complaint and you often have pains and that, then you don't always have enough vitality to receive people. (Man).

3.1.1.2 The home is functional

A functional home meant that the home was planned, organized and adapted according to one's needs and preferences. The home supported routines, for example, by the way things were placed, thus enhancing daily activities. Knowing where things were saved energy and made daily activities easier, and in this way, daily activities that were important for health could still be performed to the older person's satisfaction.

It's getting more and more important that I put everything in the right place, so that I don't need to run and look for things (...) because then you don't remember where you put them. Yes, I'm very careful about that! I have become more orderly and careful over the years because it makes life easier (...). (Woman).

Having close and easy access to a food store, library, primary health care center etc., enhanced daily life and contributed to independence. Being able to go for a walk, do some shopping etc., prevented isolation and inactivity, and enhanced feelings of still being able to participate in social life. Negotiating the advantages of a move an older woman expressed it in this way:

Yes, it's a great advantage. It's incredibly good (...). It's the best in terms of material things that I got a flat like this, so central. If you have forgotten to buy something you can go out again and buy it (.) and if you have nothing to do you can go to the library and sit down and borrow a book or something. (Woman).

On the other hand, the negative consequences of not having a functional home were illustrated by this woman:

Well, it's not so nice (to have to move), but I feel that maybe I have to anyway, I can't cope (...) It's not practical. And there you can go out with a rollator or whatever ... Or the wheelchair. (Woman).

Nice surroundings with visual and/or physical access to green areas, e.g. by having a balcony or terrace, or being able to view trees and green areas from a window, provided an opportunity to relax. In this respect, an accessible private garden or a small terrace provided important opportunities to go outdoors. At the same time, having a garden to take care of could be a considerable practical burden and was something that bothered the very old peoples' minds.

3.1.2 Having an inner driving force to maintain health

The very old people interviewed had a strong inner driving force to maintain health despite declining capacity. They constantly negotiated their life situation, and prepared for changes. They took action to maintain health and well-being within their own home. They adopted different adaptive strategies, while at the same time constantly challenging themselves in order to maintain their capacity. From the analyses two subcategories emerged: *Challenging themselves* and *Utilizing adaptive strategies*.

3.1.2.1 Challenging themselves

The very old people constantly challenged themselves in different ways, and were persuaded that it was beneficial for their health. They performed physically and mentally demanding activities in order to be independent as long as possible. For example, still doing the laundry or climbing the stairs just to stay fit means stretching one's physical limits, thus avoiding the experience of dependence and declining health. The very old people also strove to avoid mental decline, to keep mentally fit by doing crossword puzzles, reading and keeping up-to-date with what is going on in the world. One woman expressed her rationale behind this continuous challenging as follows:

*No, I don't think that everything has to be so easy. I don't think it has to be that way (...).
Well, I do think so, yes! I haven't got anything against that (challenges). (Woman).*

As part of their constant challenging of themselves, the very old people also negotiated their own housing situation. Thoughts on relocation were intertwined with their determination to stay put. In this process, the participants to the greatest extent possible avoided meeting

people frailer than themselves in order not to be reminded of their own vulnerability and to gain positive experiences from staying put:

No, I wouldn't do it voluntarily (move to sheltered housing), (...), but I can very well think of living here and getting help three four five times a day, that wouldn't worry me. I think I'd rather go on living here with a lot of help. It's a different atmosphere, there's so many sick people you see around you, here you see healthy people, I think that also means a great deal (...) (Man)

3.1.2.2 Utilizing adaptive strategies

In order to remain active and participating, the very old people utilized various adaptive strategies directed towards activities, the home, and themselves. They negotiated what is worth struggling for and what kind of activities can easily be handed over to others, or completely given up. Activities were often reorganized and adapted so that they could be performed differently but still independently. For example, while still being aware of the importance of eating healthily, the very old people often had meals that were easy to cook:

I buy an awful lot of ready meals now. That's the way it is now with diabetes, you have to eat two cooked meals a day, so I have both lunch and in the evening at five or six, so I have two cooked meals, preferably fish for one and meat for the other, pancakes or something else ... so I buy a lot ... they have good things at ICA now ... ready cooked lunches that are special with shellfish and.. (Woman).

The very old people constantly negotiated their daily life, thus making decisions as to which activities they still considered necessary to perform independently, and what they could accept or would prefer to receive help with:

I don't want to be that independent. Everything to do with... Everything to do with boring things I gladly accept. (Woman).

From the perspectives of the participants social services, including special transportation services, were not adapted to their needs and difficult to understand. When possible, they instead exchanged activities with someone else of the same age. The men, for example, helped female friends with the garden, shopping or driving, and in turn received help with cooking, cleaning and laundry. In this way, control over one's life situation was still maintained while at the same time receiving the help needed without having to have contact the social services organization:

We help each other. She has a terraced house and I help her in the summer, mowing the lawn and cutting the hedge and she washes, makes a little food, yes, we share the food. And she helps me with the laundry 'cause I can't wash by myself. At the beginning I had to do the laundry. But the ironing is the worst. She's fantastic at ironing shirts. (Man).

Home modifications, refurnishing and, in cases where the home were large, closing off areas not in use, were ways to adapt the environment to one's needs. In particular, being increasingly dependent on technical devices was an obvious signification of aging and health decline, and was avoided as long as possible:

Yes, there was prestige in that, yes (with the rollator) but yes, I would say that I've been very mobile and healthy before. Yes, it felt a bit funny (going outdoors), there were lots of people staring at me, you know, here in the building, people who know me turned round and looked at me as if from a distance, 'Are you using one of those?' (rollator).(Man).

4. Discussion

This study, conducted from the perspective of very old, single-living Swedish people, revealed quite new insights into health in relation to the home. Overall, our findings illustrate that, while constantly negotiating their life situation in relation to their vulnerability, the home

was the hub of health for these older people. Health was very much related to the possibility of being active and participating in social life in keeping with one's own preferences, and it was always evaluated in relation to their age and what they perceived could be expected in this context. The very old people had a very strong inner drive to maintain health as they were aging. They constantly challenged themselves by performing physically and mentally demanding activities, and by adopting a proactive approach. The very old people interviewed utilized a number of adaptive strategies to promote activity and participation. Given the fact that older people spend the majority of their time at home, and thus that major part of their life takes place there (Baltes et al., 1999), our overall findings are not surprising. However, our finding that the home is such a crucial prerequisite for health in very old age has not previously been highlighted and deserves further attention.

As the starting point for this discussion it is crucial to pinpoint the fact that the very old people in our study defined health in relation to their ability to be active and participating, not in relation to symptoms and diseases. More specifically, they defined their health in relation to what they could expect in terms of activity and participation on the basis of the more or less inevitable symptoms and diseases that come with old age. Even if previous research has shown that people often define health in various ways (Young, 1996), it seems as if, in line with our findings, participation in meaningful activities is crucial for perceived health in later life (Clark et al., 1997; World Health Organization, 2002; Mendes deLeon et al., 2003; Hinck, 2004). This user-based definition of health is important for the further discussion and interpretation of our results.

In this context, it is also important to highlight the fact that the participants in our study, based on the perception of their vulnerability, had a strong inner drive to maintain health.

In particular the years after age 80, often labeled “The Fourth Age”, is a phase characterized by a dynamic of losses and gains (Baltes et al., 1999). It is thus a period in life when the individual needs to struggle to minimize the effects of all the losses (Baltes, 1997) requiring constant negotiations between resources and limitations. Adopting a proactive approach (Lawton, 1989), the very old people in our study took action to maintain independence and promote activity and participation. In this process, they constantly challenged themselves, thus having to consider their own physical and mental capacity as well as the demands of the environment (Lawton and Nahemow, 1973; Lawton, 1989; Jackson, 1996) and the activities. In this respect, they were constantly involved in person-environment-activity transactions (Law et al., 1996; Fänge and Iwarsson, 2005b). Most important, in spite of the fact that such challenges are demanding, challenge and risk taking seems to be an essential aspect of health in old age as well (Jackson, 1996). That is, while preventive efforts are important in old age, e.g. in order to avoid falls and fall-related injuries, at the same time it seems important that there is still room for challenges and risk taking in the daily lives of the very old people (Jackson, 1996; Atchley, 1999; Dahlin-Ivanoff et al., 2007). To the greatest extent possible, such proactive efforts should be supported by people around the older persons.

With respect to the adaptive strategies the very old people utilized in order to maintain health, the activities were adapted to suit the participants’ needs and preferences, or were actually dropped completely if they were considered too difficult and demanding. While performing activities in an easier manner is an energy-saving strategy that has been described previously, both empirically (Lilja and Borell, 1997; Hinck, 2004; Johansson et al., 2007), and theoretically (Baltes, 1997; Schultz and Heckhausen, 1997), it still needs to be highlighted due to the fact that it is so common and requires simultaneous negotiation of home modifications (Fänge and Iwarsson, 2007; Johansson et al., 2007) or assistive devices

(Hägglom-Kronlöf and Sonn, 1999; Wahl et al., 1999; Fried et al., 2001). While home modifications contribute to independence (Stark, 2004; Fänge and Iwarsson, 2005b), and perceived health (Heywood, 2004), being an obvious signification of functional decline the acceptance of them or of assistive devices can not be taken for granted (Hägglom-Kronlöf and Sonn, 1999; Mann et al., 2002). In our study this was particularly true for mobility devices, as in spite of the fact that they provided extensive support for activity performance, having to use mobility devices outdoors in particular was difficult to accept.

More important from a health perspective, however, is our finding that a considerable number of the very old people actually gave up activities completely when they were considered too demanding. In particular, this was the case with out-of-home activities such as shopping. In some cases, the decision to abandon activities was taken out of dissatisfaction with their performance (Haak et al., 2007b), but in other cases it was due to the complex demands from the environment and from the activities. While the home environment can be adapted to one's own needs, the outdoor environment is more apt to changes that often cannot be affected (Fänge and Iwarsson, 2003). Accordingly, the environmental demands become too strong, resulting in activity drop (Fänge and Iwarsson, 2005b; Johansson et al., 2007). Giving up out-of-home activities may seem beneficial from the point of view of selecting the activities that are most easy and desirable (Baltes, 1997), and in order to retain a sense of mastery and competence in later life (Clarke et al, 2001). However, it presumably has a negative impact on the person's participation in society, and given that activity and participation from the perspectives of the very old people are such important prerequisites for health, health is most probably negatively affected by such decisions. This indicates the need to assist older people to maintain out-of-home activities, and the urgent need to create outdoor environments that

support activity and participation for all (United Nations, 1993; World Health Organization, 2002).

With respect to the decision to keep or abandon certain activities, it is worth considering the use of routines for maintaining activity performance (Pastalan and Barnes, 1999; Kielhofner, 2002). Routines might be indicators of perceived vulnerability in old age (Bouisson, 2002; Bergua et al., 2006) and as such might moderate the effects on the disablement process (Verbrugge and Jette, 1994; Bergua et al., 2006), and enhance successful aging (Baltes, 1997). In particular, routines are more important for complex activities, such as shopping and cooking, than for more basic ones (Ludwig, 1997; Fried et al., 2004). In other words, routines are more important for the activities that very old people often drop, thus indicating the complexity of the person-environment-activity transactions inherent in this process (Law et al., 1996; Fänge and Iwarsson, 2005a).

To a very large extent, in line with previous findings (Quine and Morrell, 2007), the people interviewed for this study claimed that they wanted to stay put as long as possible, actively avoiding sheltered housing. Home provides a sense of identity developed over time, and given that the home supports routines, and thus activities, it seems as if staying put would be the best health promotive strategy. However, having to move was a reality for some since they could no longer manage in their current housing, for example due to low accessibility. While forced relocation may lead to health decline, in particular among the most vulnerable older persons (Fried et al., 2004), it has been argued that relocating from one's home in old age could provide an opportunity to develop and not only be a negative experience (Oswald et al., 2002). To some extent, the participants in our study voiced the same expectations. That is, in spite of the fact that relocation seemed negative to the majority of our participants, some older

people prefer moving to sheltered housing. This challenges current national and international policy emphasizing that staying put should be the norm, and it ought to have an impact on future housing and health policies.

From a methodological point of view, this study was one of four emerging from the qualitative ENABLE-AGE In-Depth study. In relation to this, utilizing data from the ENABLE-Age Survey Study, perceived dimensions of the home, related to e.g. usability, meaning and control, as well as objective aspects, related to accessibility and environmental barriers, were found to affect health (Iwarsson et al., 2007; Nygren et al., 2007; Oswald et al., 2007) in very old age. In this respect, the findings of this in-depth study validate and are validated by other results from the same project. Moreover, our results indicate that the links between home and health are complex and affected by the different aspects of P-E-A transactions.

From a theoretical point of view, our findings are in line with the model of selection, optimization and compensation, as described by Baltes (1997). The model highlights the fact that one way of adapting to declining capacity is to carefully select which activities are still necessary and desirable to perform, to optimize their performance and, as a third step, to seek and use compensatory alternatives, such as home modifications and assistive devices. However, in previous studies the very central role of the home in this process has not been highlighted, indicating the novelty of our findings. Coming to the definition of health, the functional definition used by the World Health Organization (2001), and adopted in the ENABLE-AGE Project, seems to be validated by the very old people themselves. Most interestingly in this respect, instead of describing the desired positive health trajectory in old age in terms of “healthy aging” the World Health Organization (2002) suggests the use of

“active aging”, thus highlighting the importance of activity and participation for health during the aging process.

Moreover, our findings lend support for the complexity of person-environment-activity transactions in the homes of the very old people, thus indicating the need for all health-related interventions among very people to target this complexity without ignoring the person, the home environment or the activity. This challenges all health care staff to collaborate around older people and to contribute their own specific knowledge, whether it concerns the person, the environment, the activity or combinations thereof. Most of all, this challenges local authorities to build accessible and usable home environments that support activities inside and outside the home.

When it comes to study limitations, the fact that all interviews were conducted by female occupational therapists might have implications. In other words, traditional gender roles, personal experiences and perspectives might have affected the interviews. However, the interviewers were very aware of this potential risk of bias, and such concerns were continuously discussed and reflected upon during the interview process. Thus, potential threats to the trustworthiness due to the composition of the interviewer team were handled in a very conscious manner. The fact that all participants at the time of the interview had already been involved in the ENABLE-AGE Survey Study, as well as the fact that the interviews were conducted in the participants' homes, made it likely that credible findings and interpretations would emerge. In addition, during a long period of time different perspectives were shared and discussed with the interviewer teams in the other countries participating in the ENABLE-AGE Project.

It should be remembered that the sample of the ENABLE-AGE Project focused on very old people living alone in their own homes, and consequently, those cohabiting, living in sheltered housing or staying in different care facilities were excluded. Moreover, only very old people living in urban areas were included, thus leaving out those living in rural areas. Given the fact that the environmental conditions are very different, e.g. in terms of type of housing, availability of food stores, postal services, transportation etc. (Phillipson and Scharf, 2005), people living in rural areas might voice a different perspective on home and health relationships that the elderly in this study did. Accordingly, the findings of this study should not be generalized to other very old people living in different circumstances.

5. Conclusions

In conclusion, in health care and social services practices the home needs to be considered as the most central and important place for health in the lives of very old people. By providing safety and familiarity, the home supports activity and participation, and thus health. The very old people were very aware of their own vulnerability, and constantly negotiated their daily life in relation to this. They had a strong inner drive to maintain health, and in order to prevent decline, they took action and used different adaptive strategies targeting person-environment-activity transactions. Our findings have implications for intervention planning, and the need to put more focus on the opportunities for activity and participation. Furthermore, they also challenge current national and international housing policy emphasizing the benefits of staying put, and can thus contribute to a more diverse view of what kind of housing arrangements are optimal for very old people.

Conflicts of interest

The authors have no financial or personal conflicts of interest.

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