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Synthesizing ENABLE-AGE research findings to suggest evidence-based home and health interventions

Running title: ENABLE-AGE research synthesis

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ABSTRACT

As the quest for knowledge transfer from research to practice and policy contexts is growing stronger, researchers need to develop strategies for synthesizing research findings. Since home environments constitute an important context for the delivery of health care and social services to older adults and people aging with disabilities, research in this field can serve as an example for such endeavors. Using 35 original publications and one un-published PhD dissertation based on the European ENABLE-AGE Project we aimed to demonstrate a systematic approach to synthesize research findings generated by large research projects as the basis for evidence-based interventions. The synthesized findings highlighted the complex interactions between objective and perceived aspects of housing and aspects of health in very old age, impacting on, for example, residential decision-making. Independence in daily activity is influenced by the socio-cultural care and service context. A familiar and safe neighborhood, social network, and a good supply of services are important to perceptions of participation. Going further, we suggest housing-related interventions which address problems and challenges related to ongoing demographic changes. This article contributes to the development of strategies for knowledge transfer, connecting research and practice and policy contexts struggling to meet the societal challenges that accompany population aging.

KEYWORDS: *ENABLE-AGE, implementation, knowledge synthesis, research communication*

INTRODUCTION

In light of global aging and the growing knowledge base produced by gerontologists, the call for knowledge transfer from research to practice and policy contexts is growing stronger. Demographic change puts pressure on existing welfare systems (Newbold & Hyrkäs, 2010) and the costs of social services increase significantly when large proportions of the population reach advanced age. Older adults state that they want to continue living in their present home and avoid relocation (Lampkin, 2012), which corresponds to the aging-in-place policies of many Western countries. For those who have to relocate, there is a high demand for housing options that meet the specific needs of sub-groups of older adults. There is an urgent need for an evidence base to guide new or improved interventions for housing provision as well as the delivery and organisation of health care and social services.

An evidence base (Craig et al., 2008) is traditionally built on systematic literature reviews. However, this approach usually fails to deliver insights that represent the essence of large-scale research projects which address complex sets of research questions on a specific topic. Typically, the findings of large interdisciplinary research projects are published in multiple journals over many years, a situation where the coherence and essence of such research endeavors is lost. Consequently, interested readers must compile the findings themselves to grasp the full picture. To encourage researchers to synthesize and integrate the findings of major research projects, structured methodology is warranted.

During the latest decades, the focus has shifted from diffusion of knowledge to implementation, which represents a more active process of utilization of research results. Promising development of theories and methods for research utilization has been seen, and useful overviews of such frameworks are available (e.g., Rycroft-Malone & Bucknall, 2010). Using a large longitudinal European project on home and health in very old age as an example, we will describe a structured and rigorous methodology for synthesizing the project's empirical knowledge, which will then be used to suggest new or improved interventions for housing to support the aging population.

The ENABLE-AGE Project

The main objective of the ENABLE-AGE Project (Iwarsson et al., 2007) was to examine the home environment and its importance in healthy aging. The project's main theoretical underpinnings were the International Classification of Functioning, Disability and Health (WHO 2001) and the ecological theory of aging (Lawton & Nahemow, 1973). The conceptual framework included objective and perceived aspects of home and health, quantitative and qualitative as well as mixed-methods designs were used. In addition to person-environment (P-E) relations at the micro level, the project also considered the macro level in terms of legislation, housing regulations, and socioeconomic standards.

The ENABLE-AGE Project targeted community-residing, very old, single-living inhabitants in Sweden, Germany, the United Kingdom, Hungary, and Latvia (Iwarsson et al., 2007). During 2002-2004, participants completed structured interviews and researchers administered assessments and observations at baseline (N=1,918) and a one year follow-up (N=1,356). In parallel qualitative data was collected (N=190) (Sixsmith et al., 2014). From 2005 additional follow-ups were conducted in Sweden, Germany and Latvia, and comparable data on a core set of variables extend over a >10-year period. In Sweden, death dates and dates for relocations were retrieved from public registers for up to 12 years after baseline. Further longitudinal qualitative data was collected in accord with the research questions of specific sub-studies. Several of these studies had a cross-national or comparative design while others aimed to deepen knowledge on national specificities (see Table 1).

SYSTEMATIC SYNTHESIS OF EMPIRICAL FINDINGS

To synthesise the empirical findings from the project we applied a pragmatic synthesis approach (see Iwarsson, Ståhl, & Löfqvist, 2013) inspired by the principles of narrative literature reviews (Green, Johnson, & Adams, 2006). We used all peer-reviewed original publications from the ENABLE-AGE

Project, published from 2004 until June 30, 2013 (N=47). In order to include results considered important but not published in original papers due to the traditional format of PhD dissertations in Germany, in addition an unpublished PhD dissertation from Heidelberg University was included (Naumann, 2006). As 12 of the original papers reported methodological overviews or method studies, those were not included in the primary data source for the knowledge synthesis. Accordingly, the synthesis of the empirical findings was based on 35 original publications (see Table 1) and the German PhD dissertation.

< Insert Table 1 about here >

The analysis began with a one-day workshop in which the co-authors of this article engaged in an iterative, systematic working process. During this workshop, the aim and scope of the synthesis were defined. The first author (Iwarsson; PI of the ENABLE-AGE Project) was assigned the main responsibility for the analysis. One of the co-authors (Schmidt) had a general knowledge about the ENABLE-AGE Project but was not actively involved in the research, and was thus able to give input from an external perspective. One co-author (Wahl) who had a core role in the ENABLE-AGE Project was only engaged late in the analysis and served to validate the findings.

As an introductory step to subsequently suggest interventions based on the findings, the original themes at target for intervention from the ENABLE-AGE Project were revisited and linked to current developments in policy and practice. Accordingly, five overarching intervention themes were identified *a priori*: “Daily independence and autonomy,” “Home- and neighborhood-related identity and attachment,” “Supportive housing environments,” “Residential decision-making,” and “Involvement in life situations (i.e. participation).” Two-three co-author teams were responsible for the analysis of each of these intervention themes.

To facilitate the analysis, the abstracts, results and conclusions of the publications were extracted. Since the PhD dissertation was written in German, it was used in the analysis based on input from the German-speaking co-workers. To get a sense of the total material, before the actual analysis, all co-

authors read the included papers in their entirety. Thereafter, applying as naïve reading as possible, we concentrated on the extracted material using the basic principles for content analysis (Elo & Kyngäs, 2008). Each two-three co-author team then worked independently and deductively focused on the data relevant to their intervention theme. For each of the five themes, a crude categorization of the content was made and text portions considered relevant were extracted, preserving references to the original papers (see Table 1). Thereafter, each co-author team examined the material extracted for their respective intervention theme inductively, thus producing categories subsequently used to structure the evolving synthesis of findings (marked in italics under the heading “Synthesized Findings”) .

Thereafter, draft findings were compiled and distributed for review to all co-authors except Wahl. At a next meeting the evolving material was thoroughly discussed, feedback was collected and further refined. Each co-author team continued their work independently and produced a coherent analysis based on their material. Continuing the inductive analysis and including input from Schmidt, Iwarsson then compiled the synthesized findings which were submitted to all co-authors (except Wahl) for additional input. External input was provided at a symposium at the GSA 66th Annual Scientific Meeting, New Orleans, U.S. (Iwarsson & Gitlin, 2013) as well as a joint informal seminar with a U.S. research team representing intervention studies expertise. Finally, Iwarsson once again revised the text and circulated it to all co-authors for a final round of input and validation.

SYNTHESIZED FINDINGS

The complex interplay of aspects of housing and health in everyday life

Overall, the findings highlighted *the complexity between aspects of housing and aspects of health* in very old age. While posing challenges for cross-national research (study 18; see Table 1), in terms of objective aspects of housing, environmental barriers are common and rather similar across countries. For example, indoors “turning motion of wrist required” in kitchen/laundry room and in general in the dwelling, “use requires hands” in kitchen/laundry room, hygiene room, and in general in the dwelling, “loose mats,” and “mirror in hygiene room only at height for standing,” are very prevalent in different European countries. In the closest exterior surroundings, “path surfaces not level,” “no/too few seating places,” “poor illumination of walking surfaces,” and “refuse room/bin that can only be reached via steps” are likewise very prevalent. The differences are mainly attributable to different housing standards (study 17). The magnitudes of accessibility (P-E fit) problems depend on how national guidelines for housing design are defined. On the macro level, national specifications for housing design determine the proportion of dwellings that are accessible (study 10). Over shorter time intervals, the magnitude of housing accessibility (i.e., P-E fit) problems among very old people is stable, but changes in how single environmental barriers contribute to the magnitude of problems deserve attention. An important empirical observation is that most of the variance in P-E fit is attributed to the combination of functional limitations of the individual. This implies that the magnitude of accessibility problem varies among individuals due to the complexity and severity of their functional limitations even when the occurrence of environmental barriers in the dwelling and the closest exterior surroundings is identical. Accordingly, the increasing magnitude of accessibility problems over time is generated by the increasing complexity of individual profiles of functional limitations rather than by changes in the manifestation of environmental barriers (study 17). Those with good accessibility at home, who perceive their home as useful and valuable for activities, and who think that others or fate are marginally responsible for their housing situation are more autonomous in daily life, have a better sense of well-being and fewer depressive symptoms (study 28).

Despite similarity in number of environmental barriers, people aging with a chronic disease such as Parkinson's disease live in housing with more accessibility problems, and are more dependent in activities of daily living (ADL) than very old people in general (study 25). Also, those with more complex profiles of functional limitations perceive their homes as less usable for activities and seem to be less attached to their homes (studies 25, 31). Considering falls specifically, individualized optimization of the home environment based on valid data on P-E fit (i.e., concentrating on the environmental barriers that generate accessibility problems based on the profile of functional limitations) and attention to perceived aspects of usability impeding activity seem to have a higher preventive potential than the traditional reduction of environmental barriers following generic fall risk assessments (study 14). Among the specific environmental barriers that generate the most P-E fit problems, "lack of handrails at entrances" is significantly associated with a higher mortality risk (study 29). In contrast, there are indications that indoor environmental barriers such as stairs between floors making physical exercise necessary might have a slight health protective effect (study 33).

The complex *interactions between objective and perceived aspects of housing* (studies 26, 34) highlight the importance of living in a home that is familiar, meaningful, and secure; qualities that signify autonomy, independence, and participation and are linked to perceived health. The home not only enhances autonomy and participation, it is imbued with personal meaning (study 7) and personal objects that create a familiar setting full of memories (studies 3, 9). Studying cross-sectional as well as cross-cultural associations, among very old people housing accessibility is positively associated with perceiving the home as usable and imbued with meaning as related to behavior as well as with not being dependent on external control (study 26). People who have lived in the same neighborhood comparatively longer are more satisfied with their homes, and they perceive them as being more usable and meaningful (study 6). Housing-related control beliefs explain variation in ADL independence, for example, those with lower external control beliefs are more independent though there are some differences among countries (study 35). Cross-sectional findings from Sweden show that accessibility problems influence life satisfaction as well as perceived health (study 16), while longitudinal findings from Sweden and Germany show that

accessibility and control beliefs are consistently associated with autonomy and well-being. Accessibility is more strongly associated with daily independence, and external control beliefs more strongly associated with well-being (study 35). Accessibility predicts short-term changes in daily independence and depression, and there are significant interaction effects between accessibility and control beliefs and changes in life satisfaction and depression. The predictive role of accessibility on changes in life satisfaction and depression weakens as external control beliefs increase (study 34). It should be kept in mind that when studying sub-groups of very old people categorized according to independence in different national contexts, there are great diversities regarding the housing and health interplay (study 32). In countries such as Latvia where the overall standard of living in very old age is low (particularly among women), factors beyond housing impact on life satisfaction (study 11).

To stay or to move: Residential decision-making

Living in a functional and usable home is necessary for independence that in combination with sufficient skills and not being too frail enables very old people to avoid relocation (study 1). As to *residential decision-making*, those living in dwellings that have been modified and live in single-family dwellings live longer in their current housing (study 13). Very old people view assistive technology or housing adaptations as supporting independence and aging in place, but they also adapt to everyday changes that lead to the creation of new meanings as circumstances change (study 8). Reasons to move reflect the urge to maintain independence, stay in control and avoid loneliness, and are mostly expressed reactively.

Reasons not to move reflect strong attachment to the home and neighborhood as well as practical aspects such as economic strain and fear of losing continuity of habits and routines (study 21). Predictors of relocation differ between relocation to ordinary housing and special housing. That is, dependence in specific instrumental ADL such as cooking or cleaning is related to both types of relocation. Perceived functional independence and type of housing are related to a move within the ordinary housing stock. In contrast, cognitive deficits and housing accessibility problems are related to a move to special housing (study 3).

Personal and environmental influences on aging in place

The *use of assistive devices* increases and implies changes in use and need also in a short-term perspective in very old age (studies 19, 24). This is particularly true for mobility devices (MDs) (studies 19, 23) as they support independence and facilitate participation (studies 12, 20, 22). At the macro level there are marked differences among countries, with less availability of MDs in Eastern than in Western European countries (study 24). Positive outcomes of MD use aside, the devices add to the complexity of home and health dynamics and are important in P-E interactions (studies 20, 22), particularly among those aging with chronic disease (study 9). Access to different types of MDs, and their forms and functions are important for optimal use (studies 20, 22). It should also be noted that MDs to some extent are stigmatizing, which may interfere with their use (study 23).

Across the studies, health is described in terms of being able to manage daily activities at home and participate in society. *Personal factors*, such as believing in one's own capacity, play a large role in independence and autonomy while aging. Adaptive strategies are used to manage everyday life independently and challenge oneself to maintain functioning (studies 2, 4, 7). Still, independence is also influenced by the *socio-cultural care and service context* (study 15). Challenges to independence due to the natural course of aging seem to be easier to accept and cope with, while changes due to disease (study 21) are reason to consider major environmental adjustments (study 3). In very old age, people reach turning points where it is no longer possible to keep on as before, but independence is nonetheless very important even when functional capacity becomes limited (study 8). By performing activities differently but still autonomously, people continuously negotiate with themselves concerning possible reorganization and adaptation of activities and environments both within and out-of-home (studies 12, 33). A positive attitude and acceptance of help seem to preserve the perception of autonomy even when independence is compromised (study 33). Perceptions of and attitudes about independence vary according to health status; the importance of getting out, taking a walk and being with others is valued among those with better

health. Those in poorer health prioritize the ability to perform home-based activities independently (study 4).

Strategies for maintaining participation

A familiar and safe neighborhood, social network, and a good supply of services are important to *perceptions of participation*. People develop strategies and adaptive behaviors as they strive to maintain independence and participation (studies 12, 22). Accessibility and possibilities for social interactions that support continued performance of meaningful activities in the neighborhood are key. Living close to friends and relatives and having access to cultural events in the vicinity are related to higher levels of togetherness-oriented as well as performance-oriented participation (study 6). Neighbors are a crucial social contact group providing stable and good relationships. Changes in this element can have negative consequences (study 33). As to gender differences, it seems as if men have more difficulties than women in establishing new social contacts (Naumann, 2006). For togetherness-oriented participation, having access to local shops, parks, etc. facilitates participation, and good local transportation is critical. Being acquainted with the area and knowledge of available services support retained independence and sense of wellbeing (studies 1, 4). Being able to leave the home and go for a walk prevents isolation and inactivity (study 2), and enhances feelings of participation. As health declines, the personal repertoire of out-of-home activities diminishes and participation in activities within the home becomes more important (study 5; Naumann, 2006). The home becomes a place for maintaining contacts with friends, relatives, and neighbors (studies 1, 5). For those physically confined to the home, links to the outside world such as looking out of the windows and experiencing beautiful views or children playing supports participation (studies 5, 33; Naumann, 2006). Technology such as e-mail or other web-based activities is a means of keeping in contact with younger generations (study 4), enhancing participation. Radio and TV also serve to keep up a sense of participation (studies 5, 33). Such shifts in patterns of participation represent an active and creative adaptive strategy (Naumann, 2006).

TOWARDS EVIDENCE-BASED INTERVENTIONS

Weaving together the synthesis of the empirical findings with the intervention themes identified *a priori*, in an iterative process, we developed suggestions for evidence-based interventions at different levels.

Interventions at the individual and group levels target older adults (clients, families) as well as professionals directly related to clinical or societal practices. Other types of interventions represent knowledge transfer efforts in undergraduate and graduate education producing professionals for health care and social services, continuing education for practitioners in relevant fields, or communication activities involving stakeholders and the general public). Although policy changes are often not direct interventions, they are typically necessary in the implementation of interventions (e.g. provide financial support for staff or infrastructure necessary for interventions to be implemented to benefit the target population). More direct policy interventions relate to mandated requirements placed on private and public sector organizations (e.g. establishing building codes) or organizational policies that, for example, mandate how and which services are delivered.

Interventions for daily independence and autonomy

The synthesized findings can be used to develop evidence-based home care and social services that support independence and autonomy. Services and interventions should not be prescribed but rather negotiated with older adults to take into account their personal needs and preferences. For example, regarding preventive efforts to reduce falls, the P-E fit approach is a means for developing individualized interventions. On the group and general population levels, public health and self-management programs that empower older adults to plan more efficiently for their home and health needs should be developed.

Interventions for home- and neighborhood-related identity and attachment

Current home modification and housing adaptation services need to progress beyond the predominant focus on the physical accessibility of dwellings. That is, greater awareness of perceived aspects of housing and neighbourhoods among very old people is needed in housing counselling and housing provision. Attention should be paid to psychological issues such as the meaning of home and external control beliefs. Professionals engaged in counselling related to housing in very old age should be made aware of the role of biographically-developed bonding between person and place over time. That is, housing adaptation and relocation counselling should negotiate changes in the housing situation with respect to individual perceptions of meaning of home. Professionals should strive to make older adults more aware of their individual goals and expectations regarding home- and neighbourhood-related issues. As aging and changing life situations prompt change in housing situations, more attention should be paid to dialogue on such issues. Evidence-based intervention programs should include systematic procedures to identify personal needs and goals as well as information on specific diagnoses, profiles of functional limitations, psychological factors, and levels of dependence in daily life activities. Strategies for describing individual cases that integrate physical, psychological, and environmental aspects are crucial. To change current practices, group level interventions are needed, such as new educational programs for planners and designers as well as staff involved in housing adaptation and relocation counselling services.

Interventions for supportive housing environments

The quality of individual housing adaptations can benefit from implementation of tools in the assessment arsenal developed and tested in ENABLE-AGE Project. To also support activity and participation in the dwelling and outside the home, the services should include systematic assessments and counselling targeting also the exterior surroundings and neighborhood services. Objective and perceived aspects of housing should be included in needs assessments and respected in the planning of individualized interventions. The home must be approached as a place of meaning, and when recommending housing adaptations, interventions should be as closely associated with normality as possible. At the professional level, assessment results that describe the home and health situations of people aging with specific

diagnoses can be used to develop targeted interventions. At the policy level, housing standard specifications should be updated. Legislation and guidelines for housing design and housing provision must account for today's older adults' situations, including information about type profiles of functional limitations and disease-specific functional declines. This information will allow professionals to make suggestions for interventions that are tailored to individual needs not only for the time being but taking expected disease or frailty development into account. Also at the group and societal levels, methods based on ENABLE-AGE Project findings could be used in surveys for detecting housing stock with particularly serious accessibility problems.

Interventions for residential decision-making

Older adults should be actively involved in processes related to housing provision, using a holistic perspective that takes objective as well as perceived aspects of home into consideration. Our findings underscore the need to develop more efficient relocation counseling services to help very old people deal with ambivalence, fears, worries, and practical considerations about their housing situation. Additional counselling after a move is also needed to facilitate place integration, providing information on possibilities in the new environment, facilitating awareness and promoting active choices. More in-between housing options are needed as alternatives to assisted living facilities; this could be accomplished through policy changes. Actions that support empowerment of older adults with respect to housing options can contribute to the change of attitudes and knowledge among politicians and housing providers.

Interventions nurturing participation

At the individual level, each individual's situation in terms of personal habits, social support, and physical environment factors should be taken into account so as to support participation. Home care and social services should be sensitive to very old people's self-defined goals for participation and meaningful lives. Such development is dependent on change of attitudes and increased knowledge about the diversity of individual home and health situations and needs of very old people among politicians as well as

professionals. Education programs and novel ways of knowledge dissemination that raise awareness of age stereotypes and change the societal perceptions of aging are needed to nurture the development of individualized interventions with capacity to support participation among older adults.

CONCLUSION

In this article, we have presented a systematic approach to synthesize the findings of a large longitudinal cross-national research study; the ENABLE-AGE Project. We suggest interventions to address some of the problems and challenges related to ongoing demographic changes. Applying transdisciplinary approaches (Haire-Joshu & McBride, 2013), these interventions should next be discussed with older adults and their interest organisations, followed by prioritization and development of new or optimized interventions (Kylberg, Haak, Ståhl, Skogh & Iwarsson, 2015).

Criticism can be raised regarding the pragmatic knowledge synthesis approach we adopted to compile the findings of a wide range of different publications from the one large project. Since we used a systematic procedure and followed acknowledged principles for narrative reviews (Green et al., 2006), the findings should be considered trustworthy. Readers might question why we restricted the synthesis to the findings of our own project, without conducting a systematic search across the broad literature on home and health in very old age. Such reviews have already been published (e. g., Annear et al., 2014; Wahl, Fänge, Oswald, Gitlin, & Iwarsson, 2009), but typically do not give a comprehensive account of the collated findings of large research projects from which original publication on different topics have been published, not necessarily captured by a review based on specific aims. The very point of the present article is to present an approach to knowledge synthesis different from that of systematic literature reviews, exemplifying how the results of large projects that produce a lot of results could be compiled in their own right. The evidence-based interventions presented here will further communication with a variety of stakeholders.

The methodological contributions of the ENABLE-AGE Project include new project-specific instruments (e.g., Iwarsson, Horstmann, & Sonn, 2009) and qualitative approaches (e.g., Haak, Himmelsbach, Granbom, & Löfqvist, 2013) as well as optimization of existing methods (Carlsson, Haak, Nygren, & Iwarsson, 2009; Iwarsson, Haak, & Slaug, 2012). With a multitude of high quality data at hand, interdisciplinary teamwork can refine existing concepts, define new concepts, and produce methods that lend themselves not only to advance research but also in education and practice contexts.

While maintaining high scientific standards, researchers must find ways to make their research more appealing and easier to access. With this paper we have striven to contribute to the much-needed development of strategies for knowledge transfer, connecting research and practice and policy contexts struggling to meet the societal challenges that accompany population aging.

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TABLE 1 Empirical studies based on the ENABLE-AGE project, used for the knowledge synthesis (Jan 2004-June 2013), N=35

Number ^a	Author constellation	Year	Publication title	Journal and citation details
1	Dahlin-Ivanoff, S., Haak, M., Fänge, A., & Iwarsson, S.	2007	The multiple meaning of home as experienced by very old Swedish people.	Scandinavian Journal of Occupational Therapy, 14, (1), 25-32.
2	Fänge, A. & Dahlin Ivanoff, S.	2009	The home is the hub of health in very old age: Findings from the ENABLE-AGE project.	Archives of Gerontology and Geriatrics, 48, 340-345.
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^a Used as citation indicator in the Synthesis of empirical findings section. Note: The German PhD thesis referred to in the Synthesis of empirical findings section and the methodological studies from the ENABLE-AGE referred to in the Concluding remarks section are listed under References.