SYSTEMATIC LITERATURE REVIEW ON THE CONCEPTUALISATION OF AUTONOMY IN THE NURSING HOME

Master Thesis

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Abstract

Background and Objectives: Autonomy is one of the three basic psychological needs, that are identified by the Self-Determination Theory (SDT) as essential for psychological wellbeing across the whole life span. The SDT understands autonomous behaviour as choiceful and volitional, which often can be hard to adopt for elderly residents in the scheduled living environment of nursing homes. This review study constructs the concept of autonomy from the perspective of elderly nursing home residents to gain an understanding of what specifically characterises their autonomy-needs.

Research Design and Methods: A systematic literature review was used to qualitatively synthesise all study records found that provide self-reports of residents on autonomy in the nursing home (n = 15). Relevant themes of autonomy as described by nursing home residents were identified and compared to the components of autonomy as defined within the SDT to evaluate whether the theory matches the needs of nursing home residents.

Results: Five themes as part of the conceptualisation of autonomy by nursing home residents were identified: Choice and control, Independence, Freedom and resources, Being seen and heard and Chosen dependence and competence. These compare to the definition of autonomy within the SDT, which appears to take a universal approach, taking variations in needs into consideration that match the perspectives of nursing home residents.

Conclusion: The main ingredient of autonomy for nursing home residents was identified as having meaningful choices that affect themes like daily activities, decision-making and (in)dependence. Accordingly, the SDT definition of autonomy was specified here to set a basis for wellbeing interventions in nursing homes to increase resident autonomy.

Introduction

As the majority of the global population is expected to reach a life span of more than 60 years (WHO, 2015), the demand for nursing homes is growing. With increasing numbers of residents, nursing homes are confronted with challenges to offer quality support for every individual. Whereas clear guidelines are given on what physical and medical support is demanded, it is less clear what characterises the psychosocial needs of nursing home residents, which are essential to be met for their psychological wellbeing (Kasser & Ryan, 1999). Here, the need of autonomy moves into focus of elderly care studies and practice, since its' satisfaction generally seems to be at risk within the institutional setting (Lyttle & Ryan, 2010; Vallerand & O'Connor, 1989).

Autonomy is defined within the Self-Determination Theory (SDT) (Ryan & Deci, 2000) and its sub-theory the Basic Psychological Needs Theory (BPNT) (Ryan, 1995) as one of three basic psychological needs. This means that, among the basic needs of competence and relatedness, autonomy is assessed as essential for vital and healthy functioning by providing resources that facilitate thriving, growth, and integrity (Deci & Ryan, 2017; Ryan, 1995). The SDT states that the vitality of human wellbeing is mainly influenced by levels of volitional or self-determined behaviour, setting the focus on the importance of autonomy for wellbeing (Deci & Ryan, 2017). Deci and Ryan (2017) conceptualise autonomy as the need to self-regulate one's experiences and actions. It mainly expresses personal choice, which offers the free ability to organise and prioritise one's values and inclinations (Deci & Ryan, 1991; Deci & Ryan, 2017). Autonomous behaviours are therefore self-endorsed based on one's own interests and characterised by feelings of freedom, volition, congruence, and authenticity (Deci & Ryan, 2017; Kasser & Ryan, 1999). Several studies show that this benefits our mental health essentially, yielding for a higher wellbeing for all people across different cultural environments and the whole lifespan (Deci & Ryan, 2017; Vansteenkiste, Ryan, & Soenens, 2020).

However, the need of autonomy appears to be at risk to remain unsatisfied for patients within the nursing home context. As Sherwin and Winsby (2010) explain, the context-related experience of greater dependency involves the likelihood that residents cannot act and decide according to their personal interests. Additionally, a link to the basic need of competence is possibly established, since autonomy seems to be easily taken from residents if they are assessed as less competent due to illnesses such as dementia (Sherwin & Winsby, 2010). This risk matches former research results, where one interview study found that more than 20% of residents experienced low fulfilment of the three basic psychological needs, including autonomy, in a somatic nursing home environment (Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012). According to the SDT, this would have diminishing effects on resident's wellbeing, resulting in for example poorer self-esteem or weakened motivation and was researched to relate to mortality in a nursing home context (Deci & Ryan, 2017; Kasser & Ryan, 1999). For a higher wellbeing, the satisfaction of autonomy appears to be essential, which manifests in higher self-esteem, life satisfaction, meaning in life and general health of residents (Vallerand & O'Connor, 1989). Among the three needs, autonomy was found to have the strongest relationship to wellbeing, where having a sense of choice appears to be of high importance for nursing home residents (Kloos, Trompetter, Westerhof, & Bohlmeijer, 2018). This link is supported by a study of Langer and Rodin (1976) who found that residents who experienced more autonomy also experienced higher wellbeing, as feeling significantly more alert, active and happy. Here, residents were for example encouraged to take responsibility and make decisions by themselves.

Accordingly, it gets visible that contextual characteristics can differ concerning the support for autonomy. This matches the explanation of the SDT that the social and cultural environment of an individual plays a major role and can set supportive or destructive conditions (Deci & Ryan, 2008; Ryan, 1995). Individuals can experience their environment as autonomy-

supportive by for example offering sufficient choices or as behaviour-controlling, where they feel to be seduced into actions based on external conditions (Deci & Ryan, 1987). As conditions often differ, it is of interest how residents view their autonomy within different nursing home environments.

Having a closer look at studies on autonomy in nursing homes, it appears that autonomy is measured in different ways in the various studies. Not only different measurement instruments are used, also the definition of autonomy is not consistent. For example, the meaning of autonomy is sometimes replaced by the concept of independence as in a study of Steinberg and Silverberg (1986) who considered independence as equal to autonomy. Contrary, Deci and Ryan (2017) describe autonomy as not equivalent to independence or self-reliance, since humans can decide to be dependent or independent based on their own will, but also forced into one of these states. Thus, behaviour according to one's own will can comprise independent behaviours, as well as dependent behaviours, where the individual willingly decides for input and guidance of others. Also, other researchers highlighted that a general debate on the conceptualisation of autonomy emerges in the research field of autonomy (Sherwin & Winsby, 2010; Vansteenkiste et al., 2020). Whereas the autonomy definition of the SDT claims to be universal among life stages and cultures, conceptual confusion emerges due to varying definitions of autonomy in the literature (Sherwin & Winsby, 2010). Hence, clarity is missing on how nursing home residents define autonomy and whether this matches the definition of choice and volition as conceptualised within the SDT.

Many studies on autonomy in nursing homes set their focus on the perspectives of staff or relatives to define and evaluate resident autonomy, whereas studies on resident's perspectives are underrepresented (Wulff et al., 2013). Gaining insights into resident's perspectives is essential for providing quality support for every individual by adapting to their needs (Van Hoof et al., 2016). By identifying resources that need to be provided for the

satisfaction of autonomy, nursing homes can focus on these aspects that contribute essentially to resident wellbeing. Accordingly, this study is interested in self-reports of residents among various nursing homes for older adults concerning their personal experience of autonomy to identify elements of importance for nursing home residents to define autonomy. Therefore, a systematic literature review was conducted to identify the conceptualisations of autonomy found in studies on autonomy in nursing homes as reported by residents. Results are compared to the conceptualisation of autonomy in the SDT, focusing the definition on choice and volition. By that, the SDT definition's applicability among nursing home residents and its universality among different contexts can be validated for the nursing home environment, contributing clarity among the conceptual debate. Based on that, this review study is interested in the following research questions:

1. How do nursing home residents define autonomy?
2. How does the resident's definition of autonomy compare to the conceptualisation of autonomy in the SDT?

Method

Study Design

To understand nursing home residents' definitions of autonomy, a systematic literature review was conducted, targeting former studies that give information on how residents view their autonomy within the institution. The review was structured according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) recommendations. To effectively combine insights from the chosen studies, a qualitative synthesis helped to construct a conceptualisation of autonomy from nursing home residents' perspectives.

Literature Search

In line with phase 1, the focus of the review was identified according to the research questions and was assisted by making use of the search framework of PICOC (Petticrew & Roberts, 2006). This structure focuses on five categories to specify component concepts that are defining the focus of the search, namely population, intervention, comparison, outcome, and context. Table 1 shows the related component concepts of the current research.

Table 1.

PICOC Framework applied to the current study to assist the literature search and its focus.

Population	Intervention	Comparison	Outcome	Context
Nursing home (for elderly) residents	Qualitative and mixed method designs	Definitions of autonomy	Perspectives on, experiences or satisfaction of autonomy	Nursing homes, including home for the aged, residential aged care facilities, geriatric long-term care facilities (international)

Search terms were recruited to identify studies that give information on the components of Table 1. First, keywords were extracted from the research question, namely ‘autonomy’, ‘nursing home’ and ‘residents’. These were the main ingredients for the literature search to identify the target group, the focus on the concept of autonomy and the context, as further specified by the PICOC framework. To specify the search most efficiently, synonyms of the keywords were collected, which were afterwards combined into search queries. Keywords and the collection of synonyms can be found in the Appendix.

Based on these, search queries were made up to test in several databases for searches within titles and abstracts. The scientific databases of Scopus, Web of Science and PsychInfo

were used, as these contain a large amount of records and peer-reviewed articles in the psychological field. Using an iterative search process, various search strings were tested and adjusted according to the fit of the found search results. When articles were found that matched the PICOC framework, but used differing keywords, these terms were added to the matrix and tested again in combination with the other keywords. By that, more suiting search results could be generated to effectively identify all relevant articles possible. During the process of finding the most suitable search string, articles were decided to be not considered that focused on nursing home staff or nurses instead of residents. Including the operators of AND NOT (staff OR nurs*) in the search string appeared to be necessary to limit the number of irrelevant hits extensively. During the iterative search process, the not considered articles by using this method were appraised as not suitable for the current review due to a diverging focus, respectively. In accordance, one search query was chosen to be used among the three databases, that turned out to give the most inclusive and suiting literature results and can be found in Table 2.

Table 2.
Search queries and information on amount of hits per database.

Date	Database	Search Query	Hits
23-04-2020	Scopus	TITLE-ABS-KEY ((autonomy OR self*determination OR freedom) AND ("nursing home" OR "long*term care facility" OR "aged care facility" OR "home for the aged") AND (resident* OR patient*) AND NOT (staff OR nurse*))	633
23-04-2020	Web of Science	TOPIC: ((autonomy OR self*determination OR freedom) AND ("nursing home" OR "long*term care facility" OR "aged care facility" OR "home for the aged") AND (resident* OR patient*) NOT (staff OR nurse*))	243
23-04-2020	PsychInfo	(autonomy OR self*determination OR freedom) AND ("nursing home" OR "long*term care facility" OR "aged care facility" OR “home for the	184

aged”) AND (resident* OR patient*)
NOT (staff OR nurse*)

Study Selection

The identification of the population, intervention, comparison, outcome and context were used as eligibility criteria, defining what studies should entail to be selected for the review. No restrictions were given on time of publishing of the articles. When screening the results in the databases, first titles were selected that appeared to suit the criteria of the PICOC framework and accordingly the focus of the research questions. These were then further examined by reading the abstract and comparing again to the contents of the framework. If the given information matched the interests of the review, these were saved for closer examination. Additionally, reference lists of relevant articles were screened to identify other relevant articles that might not be covered within the literature found by the search string.

Inclusion and Exclusion Criteria

The selected articles were screened in more detail, considering introduction, methods, results and discussion section. Here, it was examined whether the following inclusion criteria were met: (1) Article is available in English language, full-text format and published in a scientific journal; (2) Study participants were residents of nursing homes (or long-term care facilities, etc.) for elderly; (3) Qualitative or mixed method studies that gathered data on the experience of autonomy in nursing home residents; (4) Measurements included self-report data of residents in either speech or text format. Regarding criterion 2, it appeared that articles were found with different groups of participants, such as resident’s relatives, nursing staff and residents. In these cases, the sample of exclusively residents was taken into consideration for the current review, whereas data gathered by the remaining samples of the same study was ignored.

Studies were excluded that focused on the decision-making process to enter nursing homes instead of the current state of autonomy during daily living. This was chosen because the current review is interested in the views on autonomy within the environment of the nursing home, which could differ from views on autonomy before entering the facility. Based on that, a final selection of articles to include in the current research was made. Additionally, a second researcher engaged in the same literature search process, using the same search query and databases. By that, it was ensured that all available and relevant articles were selected, and the interrater reliability was checked. Cohen's kappa was assessed as substantial agreement with a value of .70 among the two researchers (Landis, & Koch, 1977).

Summary of Included Studies

A total of 1060 studies were identified through the database search process. The additional articles found by manual search and screening of reference lists were added (n = 10). Figure 1 gives an overview on the process of study selection based on the retrieval of 1070 articles within the systematic literature search.

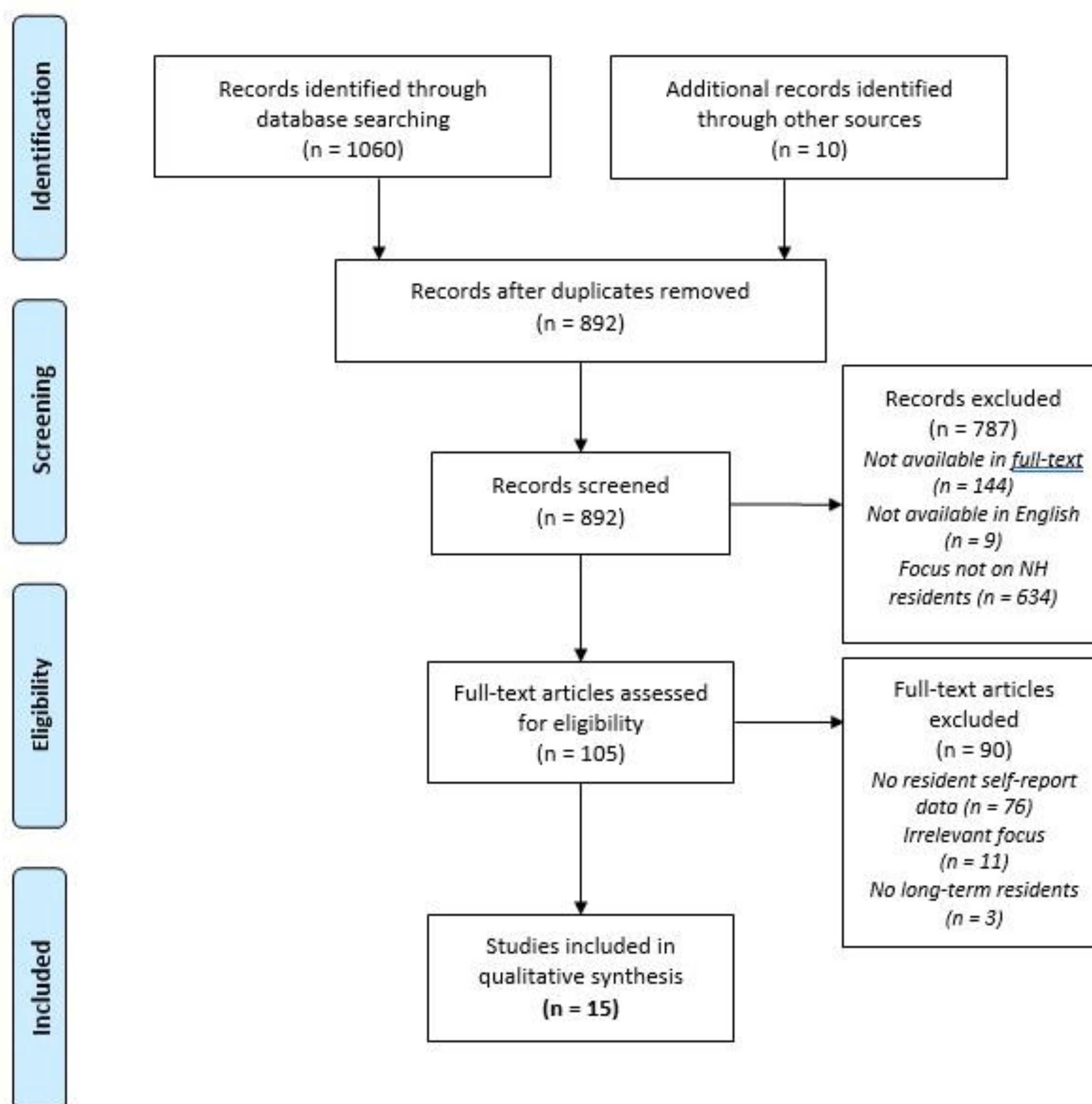

Figure 1. PRISMA flow diagram on the study selection process based on a systematic literature search.

Using the reference managing programme Endnote X9, 178 duplicates were identified within the 1070 retrieved articles. After duplicate removal, 892 articles were left to be screened according to suitability for selection, assessed by eligibility and information given in title and abstract. 787 articles were excluded, where remaining 105 articles were in line with the eligibility criteria and inclusion criteria 1 and 2. These were further assessed for selection by screening full articles, mainly focussing on method and result sections. Here, special attention was payed to the measurements of autonomy to suit the inclusion criteria 3 and 4 to select solely

self-report studies. Based on this and a checking against the exclusion criterion, 90 articles were excluded. Thus, in line with the inclusion criteria, 15 articles were selected for the qualitative synthesis.

Data Extraction and Processing

The selected articles were read independently and repeatedly to identify all details that give information on a definition of autonomy by nursing home residents. General details of the studies were extracted, namely the article's authors and publication year, interests, country of study, resident sample size (n), gender and age distributions, and used data collection and analysis methods. Specific descriptions of autonomy-related actions, wishes and feelings helped the researcher to identify the different components of autonomy inductively. All accounts that indicated an aspect of the concept of autonomy, either by measurement means, direct word use, synonym word use, or references to resulting (un)autonomous feelings were gathered. First-order constructs, meaning direct quotes of participants, as well as second-order constructs, meaning author's descriptions and summaries of the resident's self-reports, were both considered. Component descriptions were gathered for every study, before grouping these among the reviewed studies.

Descriptions of components of autonomy were grouped into themes according to similar meanings and defined based on all extracted data on autonomy components given among the studies. Within the articles, it was also checked whether contradictory values of autonomy were expressed, to consider varying perspectives of nursing home residents. Based on that, the data was synthesised into a new definition of the concept of autonomy that matched the descriptions of residents, as found among the different studies. This conceptualisation of autonomy was further used to be directly compared to the conceptualisation in the SDT to search for overlaps, contradictions, or missing component descriptions. Here, the following references were used that gave first-hand definitions of autonomy from the SDT perspectives by their authors:

"The need for autonomy refers to a sense of choice and volition in the regulation of behavior" (Ryan, Huta, & Deci, 2008, p. 153); "[…] autonomous actions are those that can be self-endorsed and for which one takes responsibility" (Deci & Ryan, 2017, p.51); "[…] we further distinguish autonomy from the ideas of independence (or nonreliance) and freedom (or lack of constraints)" (Deci & Ryan, 2017, p.51); "An autonomous act is one done freely and willingly by the actor" (Ryan et al., 2008, p. 157); *"But, within SDT, autonomy refers not to being independent, detached, or selfish but rather to the feeling of volition that can accompany any act, whether dependent or independent, collectivist or individualist" (Ryan & Deci, 2000, p. 74).*

Results

The study sample was assessed as heterogeneous, as aims of the reviewed studies were rather diverse. The main focus on resident experiences of autonomy (or self-determination) as interest of the study was given in three articles. Others focused on the experience of quality of life by nursing home residents (n = 4); general perceptions of daily life in the nursing home, sometimes including special focus on certain experiences such as mealtimes or loneliness (n = 5); ethical challenges (n = 1); the experience of aged care living for younger people with dementia (n = 1) and an implementation of a systematic inquiry (n = 1). What all articles have in common is that they provide self-report data in forms of descriptions of autonomy within the nursing home by residents. In table 3, an overview is given on the 15 selected studies sorted by authors, presenting information on general details of the studies.

Table 3.
Overview characteristics of included studies, giving information on study interests, country, setting (e.g. nursing home (NH)), N (resident participants), their gender, age and methods used in data collection and analysis.

	Article (Authors + year)	Interests	Country	Setting	N	Female % / Male %	Age Information	Data collection / analysis method
1	Ball, Whittington, Perkins, Patterson, Hollingsworth, King, & Combs (2000)	Resident's views of quality of life (including autonomy)	Georgia	17 assisted living facilities primarily for frail elders	55	89 / 11	90 % > 64; 29% > 84	Face-to-face, structured interviews / grounded theory analysis
2	Bollig, Gjengedal, & Rosland (2016)	Perceptions of ethical challenges for residents	Norway	9 NHs	25	64 / 36	66 – 100	Semi-structured, in-depth interviews / interpretive description
3	Boyle (2004)	Variations in subjective quality of life (particularly autonomy) according to setting (domiciliary care vs. long term care institution)	Ireland	45 residential and NHs	214	69 / 31	$M = 82.8$; $SD = 7.7$	Structured interviews / qualitative data analysis
4	Cho, Kim, H., Kim, J., Lee, Meghani, & Chang (2017)	Older adults' perceptions of their daily lives in NH	South Korea	5 NHs	21	85.7 / 14.3	65 – 94 ($M = 83.6$; $SD = 7.1$)	Semi-structured interviews / thematic analysis
5	Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven (2012)	Importance and experiences of residents of their basic psychological needs in the caring relationship	Netherlands	7 combined NHs (for somatic and psychogeriatric patients)	75	59 / 41	55 – 93 ($M = 79.9$)	Semi-structured interview questions and verbal comments / content analysis
6	Heggestad, Nortvedt, & Slettebø (2013)	Experiences of dignity among persons with dementia affected by NH life	Norway	2 NH units	5	80 / 20	84 - 94	Interviews / thematic analysis
7	Hellström, & Sarvimäki (2007)	Experience of self-determination of older people in sheltered housing	Sweden	5 sheltered housing facilities	11	55 / 45	73 – 93	Interviews / Qualitative content analysis

8	Palacios-Ceña, Losa-Iglesias, Cachón-Pérez, Gómez-Pérez, Gómez-Calero, & Fernández-de-las-Peñas (2013)	The significance of the mealtime experience among NH residents	Spain	For-profit NHs	26	54 / 46	62 – 96 (*M* = 86)	Unstructured and semi-structured interviews / descriptive analysis
9	Paque, Bastiaens, Van Bogaert, & Dilles (2018)	General feelings of NH residents, specifically loneliness, for strategy development	Belgium	4 NHs	11	64 / 36	74 – 92 (*M* = 84)	Face-to-face interviews / interpretive phenomenological analysis
10	Rimkeit & McIntosh (2017)	Experience of old age services among younger onset dementia residents	Australia	Old age long-term residential care facility	3	33 / 67	61 - 64	Semi-structured interviews / interpretive phenomenological analysis
11	Schenk, Meyer, Behr, Kuhlmey, & Holzhausen (2013)	Perceptions of resident's impact on their quality of life	Germany	8 NHs	41	79 / 21	Up to 80 = 33.3 % > 80 = 45.2 % > 90 = 21.5 %	Semi-structured narrative interviews / Documentary method
12	Stadnyk, Chamberlain, Warner, Earl, & Nickerson Rak (2017)	Three perspectives (residents, family members, staff) on resident's quality of life	Canada	3 NHs	6	84 / 16	58 - 90 *M* = 78.5	Interviews / framework analysis
13	Van Hoof et al. (2016)	Perspectives of residents, relatives and care professionals on factors influencing the sense of home for residents	Netherlands	4 NH facilities	34		> 54	In-depth interviews / thematic analysis
14	Van Malderen, De Vriendt, Mets, & Gorus (2017)	Implementation and challenges of a systematic inquiry (PAR)	Belgium	1 public NH	9	67 / 33	*M* = 85 *SD* = 6.7	Interviews / content analysis
15	Walker & Paliadelis (2016)	Experience and perceptions of care and possible improvement of residents	Australia	Residential aged care facilities	18	56 / 44	77 - 96	Interviews / thematic analysis

Thematic Synthesis of Resident's Self-Reports on Autonomy

The qualitative synthesis led to a new understanding of the experience of autonomy by nursing home residents. This was conceptualised by identifying five themes that were described by nursing home residents as important parts of autonomy. Accordingly, Table 4 presents each theme including definitions, example quotes of residents and authors who described the self-report data of residents, as well as citations from comparing elements of the SDT definition.

Table 4.
Overview on identified themes and numbers of article references, including definition, components and example quotes (first-order and second-order constructs).

Identified Theme (with References)	Definition	Example Quote Resident	Example Quote Author	SDT Definition
Choice and Control *(1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13, 14)*	Having meaningful options and taking decisions to feel in control about themselves	"I can do as I please. I can go to the refrigerator and get anything I want, if I want. Nobody's watching me." (Ball et al., 2000, p. 316)	"Residents experienced autonomy by maintaining control over their daily routines" (Stadnyk et al., 2017, p. 249)	"The need for autonomy refers to a sense of choice and volition in the regulation of behavior" (Ryan et al., 2008, p. 153)
Independence *(2, 3, 5, 6, 7, 9, 14, 15)*	Exerting activities independently and managing daily life individually	"Being able to feed ourselves, without help, means we are normal. We don't need to be supervised in case we cause trouble or need help..." (Palacios-Cena et al., 2013, p. 486)	"Study participants revealed two causes of their loss of autonomy, namely the need to ask healthcare workers for assistance and the obligation to wait a certain time for this professional help to arrive" (Paque et al., 2018, p. 1480)	"autonomous actions are those that can be self-endorsed and for which one takes responsibility" (Deci & Ryan, 2017, p. 51) / "Unique to the SDT is a strong distinction between independence and autonomy" (Deci & Ryan, 2017, p. 306)
Freedom and Resources *(2, 3, 4, 6, 7, 9, 10, 12, 15)*	Feeling free based on opportunities to engage in liked activities and having personal space	"Well, I'd like to (have) freedom to get around, and get around the back yard and little things like that but can't bear it when you're locked, you're locked in, you're just in all day in the room (Walker & Paliadelis, 2016, p. 8)	"Moreover, they wanted to be free to go out, but they required staff members' permission; thus, they often felt confined" (Cho et al., 2017, p. 455)	"An autonomous act is one done freely and willingly by the actor" (Ryan et al., 2008, p. 157) / "we further distinguish autonomy from the ideas of independence (or nonreliance) and freedom (or lack of constraints)" (Deci & Ryan, 2017, p. 51)
Being seen and heard	Having meaningful opportunities to communicate wishes and	"My opinions are not heard, and nothing has been fixed . . . the staff [members] just follow their	"Residents who were capable of verbalizing their decisions acted as their own advocate to direct	

(4, 6, 7, 11, 12, 13, 14)	opinions to have influence	rules . . . even though I say something to them, they don't listen." (Cho et al., 2017, p. 500)	their personal care needs. For example, Anna advocated on her own behalf to have assistance with undressing and bathing from only female staff members." (Stadnyk et al., 2017, p. 251)	
Chosen Dependence and Competence *(1, 3, 6, 9, 12)*	Receiving support as means of regaining feelings of competence	"The nurses know better, I just let them do their own thing" (Custers et al., 2012, p. 322)	"However, a few residents in homes either preferred to just cooperate with the staff or felt that it was helpful to staff if a bath was taken on a set day" (Boyle, 2004, p. 216)	"But, within SDT, autonomy refers not to being independent, detached, or selfish but rather to the feeling of volition that can accompany any act, whether dependent or independent, collectivist or individualist" (Ryan & Deci, 2000, p. 74)

The five identified themes of ‘Choice and Control’, ‘Independence’, ‘Freedom and resources’, ‘Being seen and heard’ and ‘Chosen dependence and competence’ are described in more depth in the following. Often, residents described missing aspects in their daily life that constitute their unsatisfaction of autonomy. Here, it was inferred that mentioned aspects belong to an autonomy definition of residents, since they are expressing an (unfulfilled) autonomy wish. Additionally, the identified themes can be directly compared to themes described within the SDT to obtain an overview on alignments and differences in the definitions.

Choice and control

An important theme of autonomy identified by residents, that emerged from nearly all studies concerned choice and control. The main factors described by residents to exert control over themselves and their daily lives are based on obtained choices that are legible to choose from. These factors concern around the topics of daily routines, like times of getting up, wearing chosen clothes, having breakfast or other food provisions and taking showers.

> *“Sometimes I feel like eating in my room, being able to choose what to eat...It makes me feel like I am at the wheel.”* (Palacios-Cena et al., 2013, p. 486)

Moreover, it appears to be of value to have free access to the kitchen and generally sufficient choices concerning food. Especially, residents wish to participate in decisions about themselves and their care processes by being asked what to do when and how to do it. Some differences emerged when it comes to the topic of choosing which clothes to wear. Many residents want to decide on their own what to wear, whereas some rather agree to let the staff choose.

> *“As regards having choice over what clothes to wear, one older person said it was important to have choice over what to wear as ‘you’d get very frustrated if you had to wear someone else’s choice’. […] On the other hand, one individual said that it was not important to have choice over what clothes to wear ‘because the staff choose’”* (Boyle, 2004, p. 217).

Further, some residents refer to their high level of autonomy due to their freedom in decision-making and personal choices:

> *"I decide everything myself!"; "They always ask me what I would like to wear"; "I can always make my own choices"* (Custers et al., 2012, p. 323)

However, more residents refer to insufficient choices and restrictions in control over daily routines, as well as decisions-making, lowering their level of autonomy.

> *"The majority of informants reported that they did not have much to decide at all and did not feel autonomous or self-determinant. Informants talked about problems inviting guests to share their meal, obstacles to smoke, being controlled around the clock, and that daily routines were in deep contrast to their desired level of self-determination."* (Bollig et al., 2016, p. 148)

Often, these descriptions stand in relation to the care provision by staff, indicating a discrepancy between resident's wishes, which they also verbalise, and the fulfilment of these as supported by staff.

> *"'You don't get much choice, your clothes are left out for you.' (NH resident). Another resident said that the care assistants chose what she wore even though she often told them she did not like what they picked out."* (Boyle, 2004, p. 217)

Additionally, schedules often restrict residents in feeling in control over their daily lives, where also fluctuations are experienced concerning when residents can decide what. This appears to be occasionally related to staff shortages.

> *"Similarly, one nursing home resident would have liked to have a shower twice a week, but was only permitted a weekly shower as s/he had 'to live by the rules'. Two residents in homes referred to staff shortages which restricted free choice"* (Boyle, 2004, p. 217)

Thus, many aspects are of importance for resident autonomy when it comes to the topic of choice and control, namely obtained choices, personal decision making, control over daily routines or activities and individual schedules.

Comparison to conceptualisation of SDT. A parallel between the described definition-component of Choice and control and the definition of autonomy of the SDT exists, where both perspectives assign high importance to the factor of choice (Ryan et al., 2008). Having a sense

of choice, as described in the SDT, is in line with what the residents described as engaging in activities of their interest. A major aspect here is to have the opportunity of choosing what to do, offering personal integration into individual actions. For nursing home residents this experience of choice appears to be especially important concerning activities of their daily life in the home.

Independence

In many articles, residents referred to the topic of independence. By exerting self-care and other activities (e.g. gardening) independently, residents feel self-determined and autonomous. Also, they like to exert daily activities at their personally preferred times, independent of external schedules. Mainly, they value their independence from staff, meaning that they do not feel the need to ask staff for help.

> *"Anna stated, 'I think I like that I can still be 100% independent, I can do my own clothing, I can do my own everything in here in the bathroom and I can do my own laundry.'* (Stadnyk et al., 2017, p. 249)

Often, the topic of feeding is mentioned, where residents especially value to take care of their food intake and find food choices and drinks within their reach so that they do not need to reach out to the staff. The same goes for other physical needs, such as going to the toilet or taking a shower. Here, residents who need help feel to be completely dependent on the staff, as these often let them wait or restrict their needs completely, lowering their autonomy significantly.

> *"If you want to go to the toilet, they say you just went a couple of hours ago, so that's that."* (Hellström & Sarvimäki, 2007, p. 419)

The fulfilment of resident's needs is also often dependent on the nursing home's schedules. These can stand in contrast to resident's needs and wishes, leaving them with unsatisfied autonomy to organise daily activities according to personal times. This concerns time schedules of food provision, care provision and sleeping times.

> *"I cannot decide when to go to the toilet (...) Lots of things happen on fixed times".* (Custers et al., 2012, p. 323)

Accordingly, it appears that residents wish for more independence of staff for care provision to satisfy their autonomy needs.

Comparison to conceptualisation of SDT. When comparing the theme of independence to the conceptualisation of the SDT, it is important to note that the SDT clearly differentiates autonomy and independence. According to Deci and Ryan (2017), it can be willingly and unwillingly chosen for independence. Thus, independence is not a necessary part of autonomy, whereas it can be, if an individual chooses for it based on one's personal free will. If this is the case, independent behaviours are experienced as self-regulated and self-endorsed, which is described within the SDT (Deci & Ryan, 2017), as well as by residents. This suits the concept as described by residents, where many value their independence to feel autonomous, whereas some do not assign high importance to their self-regulation of behaviour. Here it needs to be outlined, what the individual willingly choses for to evaluate it as component of autonomy according to the SDT.

Freedom and Resources

The topic of freedom was mostly related to activities in the spare time within resident's reports, where often the wish to go outside was mentioned. Residents want to feel free and relaxed, meaning that they can have sufficient opportunities to go outside when they want to and engage in activities they like. The satisfaction of this need concerns not only around unlocked doors but also the availability of staff to give permission to or help residents. Accordingly, the topic of freedom appears to depend to a large extent on resources given by the nursing facility.

> *"Flora had an interest in walking outdoors but knew that staff did not always have the time to accompany her, so she would wait until they had some free time. [...] Autonomy was negotiated between residents and staff members."* (Stadnyk et al., 2017, p. 251)

Moreover, residents value their personal space. It was mentioned that they would like to have their room treated as this, meaning that others cannot just come in without knocking or asking. Also, the general life in the nursing homes is mainly group-focused, which can contradict with resident's privacy needs in terms of having their freedom.

Many residents reported to feel restricted to go outside and engage in activities that they like due to missing resources, which contradicts their autonomy needs. Here, it appears that doors that they would wish to be locked are not, interfering with their privacy, and doors that they would wish to enter freely are not accessible instead.

> *"You lose a big part of your freedom. Everybody who comes into a nursing home will discover that. For example, you cannot just take your bag and tell them that you will go shopping. You can not do that."* (Bollig et al., 2016, p. 148)

Residents are missing support from staff to help residents who depend on it, where a significant lack of resources gets visible. This aspect and the group-focused rules and regulations appear to restrict some residents in their personal freedom. Accordingly, resident autonomy also focuses on having this personal freedom and receiving sufficient support to engage in liked activities.

Comparison to conceptualisation of SDT. The authors of the SDT refer to the concept of freedom in terms of the free will and act of an individual (Ryan et al., 2008). Accordingly, engaging in behaviours that are based on one's free will without (internalised) pressure from the outside determines the autonomous act of an individual. For residents, it is of high importance to live their freedom by engaging in activities in line with their interests, such as going outside. They would thus choose for these activities based on their free will. However, this topic mainly relates to locked doors and other constraints by the nursing home. This viewpoint deviates from the SDT, as the SDT refrains from using the concepts of autonomy and freedom as lack of constraints interchangeably, since their viewpoint rather focuses on the free and willing act (Deci & Ryan, 2017). However, both (theory and residents) see barriers in

restrictions of freedom due to controlled environments which takes the form of locked doors or schedules for residents.

Being Seen and Heard

Contributing to the satisfaction of autonomy, residents want to have the opportunity to communicate their needs, wishes and opinions. Free expression comprises for residents to engage in respectful dialogues with the staff, having room for discussion and especially being listened to.

> *"When I ask her what she thinks is important in good care, she (Grete) answers: 'that they [the carers; our comment] are not fussing, that they listen to what I have to say'."* (Heggestad et al., 2013, p. 886)

This is contributing to their feeling of having a say and thus having influence. Residents want to take part in shaping their daily lives and influence decisions and processes that are concerning them.

> *"Because there are things that we would like to have, or should have that if you don't have an avenue to express it, it may never happen."* (Stadnyk et al., 2017, p.)

Thus, opportunities to freely express oneself are needed, which are not given equally for everyone. Some feel that they are considered as not being capable of these expressions. Staff might ascribe too much disability to their state and residents feel not being listened to or their opinions and wishes appear to be considered as complaints by staff and are thus not taken seriously (Cho et al., 2017). Another issue refers to missing resources. For example, room for discussion is often not given because there is no time in the schedules for it, since not sufficient staff is existing in the facility. Residents notice this and thus feel that there is no opportunity given for them to engage in respectful discussions about their wishes.

> *"They had ideas about what activities they wanted to have but they had no forum where they could present their case. There was dissatisfaction with the existing activities, for example, because there was no room for discussion."* (Hellström & Sarvimäki, 2007, p. 417)

Accordingly, many residents feel to not have influence and thus excluded from society as well as their own environment in the nursing home. Contributing to this is that residents refer to not receive information for example on changes in their living situation or personal care, which gives them feelings of total exclusion.

> *"One informant with a catheter had not been informed about why he had to have it and eventually a nurse promised to try and remove it. The respondent belived he had the catheter to make it easier for the staff and he was frustrated that he was not included in a decision that was so important for him."* (Hellström & Sarvimäki, 2007, p. 419)

For feeling autonomous, residents thus wish to be considered and also to be informed about decisions, so that they receive sufficient information on relevant changes or schedules of the day.

Comparison to conceptualisation of SDT. Having a look at the SDT concerning the topic of 'Being seen and heard', no direct descriptions of aligning elements as part of the basic psychological need of autonomy were found. However, the processes described by residents largely depend on resources and circumstances of the environment, which could be compared to the notion of the SDT that environments can be experienced as restrictive and rather controlled (Deci & Ryan, 2017). This notion will be further elaborated on in the discussion section.

Chosen Dependence and Competence

On the contrary to the described need of independence, some residents indicated that they are happy about the staff's help, especially about care provisions of which they are not capable of by themselves. Here, choosing for dependency seems to provide them with more autonomous feelings again, as they can fulfil certain personal needs and tasks with some help of the staff, which they would not be able to engage in otherwise. It was also mentioned that some residents perceive it as helpful to follow schedules, such as taking a bath on a set day of the week or generally cooperating with the staff.

Choosing for dependence seems to be mainly based on a loss of competence, as participants refer to their own reduced cognitive or functional functioning (e.g. Ball et al., 2000). Getting help from nurses can be experienced as valuable support to either take some burden from the residents or make some activities more accessible again. Some residents also indicate that others, such as the staff or family members, can better take decisions for them which they do not feel capable of anymore by themselves.

"The nurses know better, I just let them do their own thing" (Custers et al., 2012, p. 323)

Accordingly, it appears that dependence is a component of resident's autonomy at the point of time when residents choose for it based on their loss of competence and need for support. Also, it appears that residents who do not feel competent anymore, choose to give decisions or other tasks to their family members or nurses. Based on that, they do not feel overwhelmed and avoid reducing feelings of autonomy extensively.

> *"I can't make my own decisions but they are so nice. I think it is very nice here. I am so grateful they come and help me, so I cannot complain."* (Hellström & Sarvimäki, 2007, p. 418)

Others view their loss of competence mainly as restriction, leaving them with less satisfied autonomy. Rather, they feel bothered by needing help of staff and not being able to provide self-care anymore.

> *"Sometimes it's hard. Being washed by someone else and so on ... I can't do anything myself. I can only wash my face and arms"* (Paque et al., 2018, p. 1480)

The topic of competence also relates to engagement in activities in the nursing home. Residents indicated that they cannot participate in group activities due to their physical or cognitive impairment, which is not leaving a choice for them. Accordingly, some residents feel restricted in the nursing home, not due to active exclusion, but due to their own mental or physical state.

> *"It's not that they're restricting me or anything like that. It's just that I'm unable to do it."* (Ball et al., 2000, p. 315)

Here, a state is reached where feeling autonomous seems to not be possible anymore in this aspect, as competence is missing, which in combination with possible support and chosen dependence can be experienced as part of autonomy.

Comparison to conceptualisation of SDT. The SDT highlights that dependence can be understood as autonomous when it is chosen based on one's own will, where the individual decides for input and guidance of others (Ryan & Deci, 2000). This process is described by nursing home residents for example as being grateful for the help of staff with daily tasks. However, dependence can also be a non-chosen state, which would then not equate autonomy. This state compares to residents describing their loss of competence and the related possibility to be forced into dependence to fulfil basic care needs.

Discussion

Main Findings

The aim of this study was to create a conceptualisation of autonomy from the perspective of nursing home residents. Based on that, it can be specifically identified what is needed to ensure the satisfaction of autonomy within nursing homes, contributing to meeting the psychosocial needs of residents and ensuring their wellbeing. The compiled conceptualisation was compared to the definition of autonomy as basic psychological need within the SDT, which claims to be universal among life-stages and contexts. To examine this applicability for the nursing home environment, gained insights into personal experiences of autonomy by residents as context-related perspectives were used.

The systematic literature review of 15 studies offered insights into self-reports of nursing home residents who referred to five themes of autonomy: Choice and control, Independence, Freedom and resources, Being seen and heard, and Chosen dependence and

competence. Accordingly, an overall definition of autonomy from the perspective of the sample of nursing home residents focuses on having meaningful choices and personal decision-making, engaging in activities and in daily life independently, having personal space and free time, the opportunity to express one's wishes and have influence, as well as receiving support when needed. This conceptualisation matches the definition of the SDT by setting its focus on choice and volition of behaviour (Deci & Ryan, 2017). Additionally, both perspectives view independence and dependence as part of autonomy under the condition that the individual willingly chooses for it (Deci & Ryan, 2017). Accordingly, variations in preferences exist, highlighting that the composed definition describes possible components of autonomy that do not all apply for the same individual but rather implies general nursing home residents' perspectives. Within the SDT definition, no reference to the topic of Being seen and heard was found, where room for more depth is needed to tailor the autonomy definition to the needs and perspectives of nursing home residents.

Findings in the Light of Former Research

The theme of choice and control was already examined by Kane et al. (2015) who likewise found that having meaningful choices and control over daily care matters appears to be of high importance for nursing home residents. Within their study, also the other themes found in the present review were integrated within the topic of choice and control. Also, the SDT sets the focus of autonomy on personal choice (Deci & Ryan, 2017). Accordingly, having meaningful choices appears to be a main focus among several domains, where for example also the theme of Freedom and resources essentially relates to having the choice of engaging in activities out of the nursing home. The theme of *choice* can thus be viewed as the main ingredient of feeling autonomous for nursing home residents, essentially supporting the SDT perspective of autonomy.

Where some researchers considered independence as the closest concept to autonomy (Spear & Kulbok, 2004; Steinberg & Silverberg, 1986), the current review results claim that this relation is only applicable for a subgroup of individuals. Another subgroup favours dependence to satisfy their autonomy needs, which is why a combination of these two themes into an overall theme of chosen (in)dependence can be helpful to avoid conceptual confusion. In this debate, it is also of importance to take into consideration that the research of Spear and Kulbok (2004), as well as Steinberg and Silverberg (1986), explained the link between a strive for independence as defining autonomy for adolescents, which is a diverging target group from the present study. As explained by Graves and Larkin (2006), autonomy-seeking behaviours change over the lifetime and are often adapted to the resources of one's environment. Accordingly, different groups of people or individuals opt for different levels of (in)dependence based on life stage, context, or life-changing experiences. Thus, the SDT perspective seems to provide a more universal definition of autonomy by taking these variations into consideration, as behaviours are claimed autonomous when exerted either independently or dependently, as long as these are a personal choice (Ryan & Deci, 2000), as supported by the identified theme of Chosen (in)dependence within the current study.

In this context of (in)dependence, it needs to be considered that residents who chose for dependence willingly appeared to experience diminished competence. Within the SDT, competence is defined as one of the three basic needs next to autonomy and relatedness (Deci & Ryan, 2017). Its' definition involves feeling capable of what one does, feeling effective in one's activities and feeling able to achieve one's goals (Ryan & Deci, 2000). Residence who experienced reduced competence appreciated the help of staff for tasks which they otherwise would not be capable of engaging in. Here, it can thus occur that these older adults compromise aspects of autonomy due to their personal limitations, which emerged over their lifetime (Graves & Larkin, 2006). However, residents also described how their low feelings of

competence influence their autonomy negatively due to lost capabilities to engage in activities and care tasks (e.g. Ball et al., 2000). In this sense, a low satisfaction of competence would be the basis for a low satisfaction of autonomy. Accordingly, it is supported that autonomy and competence can be interrelated in the context of nursing home resident's experiences. This is supported by the notion of Altmann, Parmelee and Smyer (1992), stating that especially for autonomous decision making, the competence of elderly to take decisions concerning their own care life must be given, as well as their desire to do so. They emphasise that such psychological phenomena can only be fully understood when seen in relation to one another. An interrelation of all three basic psychological needs was also emphasised by Kloos et al. (2018), claiming that within nursing homes the satisfaction of the needs of autonomy, competence and relatedness should be treated as interrelated and cannot compensate each other. Also, the SDT perspective puts emphasis on the importance of satisfying all three needs to ensure wellbeing (Ryan & Deci, 2000). Since much research investigated exclusively autonomy in this context, future studies should put more emphasis on examining the interrelatedness of the three needs and treating them as a unit for satisfaction and wellbeing.

Moreover, an additional theme found in this review was 'Being seen and heard' which concerned around sharing and discussing wishes or opinions. This was not directly embraced by the SDT as a component of autonomy. However, this topic emerged based on a dissatisfaction of nursing home residents with the current state of autonomy support and missing resources. Residents described opportunities for free expression and being listened to as important to have influence and feel autonomous, whereas they did not feel supported by nursing home staff in this context. Deci and Ryan (2008) explain that social contexts can be experienced as setting autonomy supportive or destructive conditions. As researched by Kasser and Ryan (1999) the experience of autonomy support within a nursing home context appears to be a major problem for residents. Autonomy support was defined here as "the extent to which

people feel supported in their ability to function autonomously, be choiceful, and make decisions" (Kasser & Ryan, 1999, p. 938). This problem also got visible in this review, as residents often referred to a lack of resources, since not enough staff is available and that schedules or nursing home rules restrict them in their autonomy (Custers et al., 2012; Bollig et al., 2016; Hellström & Sarvimäki, 2007). In contrast, a smaller subgroup of residents referred to higher satisfaction levels of autonomy in general, since they felt supported in taking their own decisions, having meaningful options and gaining feelings of freedom. Differences in satisfaction levels were also found in a study of Brocklehurst and Dickinson (1996) who relate these to varying opportunities for choice given by the care facility. For example, 62% of examined nursing homes offered choices for meals to the residents, whereas this opportunity was not given in the remaining 38% of nursing homes and as much as 68% of hospital facilities for elderly care. As explained by the SDT and replicated by O'Connor and Vallerand (1989), the link between actual opportunities for autonomy and experienced autonomy by older adults was emphasized again by the current study. Kasser and Ryan (1999) further found that the perception of receiving autonomy support (e.g. from staff) associates with increased life satisfaction, drawing back the importance of providing autonomy opportunities within nursing homes to support resident's psychosocial need satisfaction and wellbeing.

Strengths and Limitations

The key strength of this study was the development a new conceptual understanding of autonomy. Here, an overview was drawn up to understand how nursing home residents experience their autonomy. Based on this and the comparison to the SDT definition, it was specified what resident's needs are to feel autonomous. This sets a basis for autonomy support within nursing homes, increasing the practical applicability of the gathered knowledge in this study. Moreover, the systematic review and an extensive iterative search process increased the chances to generate the highest possible number of existing articles of interest for the qualitative

synthesis. Based on this, various perspectives of residents were taken into consideration for a far-reaching definition. Additionally, the reliability of the study was increased by involving a second researcher in the literature search process (Cuijpers, 2016).

On the other hand, a limitation concerns the exclusion of the search terms of “nurs*” and “staff” within the search query, which reduced the search results to titles that did not mention these two terms. Accordingly, a risk is given that articles were missed that focused on different perspectives, such as nurses or staff, but also residents, which should be included in the review study to gather all existing self-reported information on this topic. However, during the search process, a general scan of these additional articles, that were chosen to be left out, indicated an irrelevant focus of these. By an additional scan of reference lists of relevant articles, it was tried to complement any missed articles. Another limitation concerns the reviewer effect that appears to be an obstacle for literature reviews in general (Booth et al., 2016). Here, it is hardly avoidable to process the literature in an exclusively objective way, since a personal bias of the researcher naturally influences processes like study identification, assessment and synthesis or analysis. Accordingly, the definition gathered within the current study might be partial and perspectival due to a bias in the researcher’s characteristics, which influenced the information that were selected and the way these were synthesised. Lastly, the generalisability is lowered since just articles in English language were considered, where studies using other languages were thus missed.

Practical Implications and Recommendations

The results of the current study reflect components of autonomy needs of residents, that can be directly addressed in practice. For efficient autonomy satisfaction, it was found that a focus needs to be set on resources within the nursing home environment. Here, autonomy support should be directly given by ensuring sufficient staff, providing meaningful choices and personal freedom in decisions on daily care tasks and activities. The focus on autonomy support

within the environment appears to be essential for autonomy need satisfaction and thus resident wellbeing.

In practice, a focus already emerges on the satisfaction of resident autonomy as one of six domains of the growing culture-change movement (Koren, 2010), which seeks to improve the quality of care in nursing homes. Incorporating the need of autonomy is supported and its' components specified within the current study, where also attention is drawn to the interrelatedness of the basic psychological needs of autonomy and competence, which likely should be addressed in relation to each other in future. Possibly, an incorporation of competence or all three basic psychological needs in interrelation could support the culture-change movement in its effectiveness since it is taken care of all relating aspects of the basic needs of residents for their wellbeing. This widened focus can contribute to provide high-quality care for residents in nursing homes due to efficient and personal tailoring to residents' perspectives. Future research needs to address the interrelatedness of the three basic psychological needs, especially autonomy and competence, to gain insights into a holistic approach of psychological need satisfaction and add practical value to the SDT.

Moreover, the present study supports the applicability of the SDT perspective on autonomy to the context of the nursing home, as matching the needs of the residents, which were more specified here. For the efficient use of the SDT as basis for wellbeing-interventions in practice, future studies should address the universality of the SDT to support its applicability for the two other basic needs and generally among other contexts than nursing homes.

Conclusion

The present review study inferred a specified conceptualisation of autonomy from the perspective of nursing home residents and with it more clarity in the conceptual confusion debate of autonomy in this context. The autonomy definition of residents matches the SDT perspective, where a focus is set on meaningful choices as the main ingredient of autonomy for

nursing home residents, as also supported by former research. Additionally, the autonomy-component of chosen (in)dependence was identified, incorporating variations in autonomy needs according to an individuals' will and personal choice, as set into the explanation of the SDT. Accordingly, the SDT perspective seems to provide a more universal definition of autonomy by taking these variations into consideration. The presented autonomy conceptualisation offers an overview on components that are of main importance for nursing home residents and thus should be specifically addressed within nursing homes to ensure the need satisfaction of autonomy and wellbeing of residents.

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Appendix

Table A1.
Literature search matrix including possible search terms to use with Boolean operators of AND, OR, (AND) NOT as search query in databases.

Keywords	Related Terms	Broader Terms	Narrower Terms
Autonomy	Self-Determination Self-Government Quality of Life (QoL) Well*being,	Freedom Liberty Determination Free Will Decisions Decision-Making	(In)dependence Volition Choice Personal autonomy Personal decisions Independent decision Autonomous decision Autonomous behaviour Decision*making
Nursing Home	Long(-)Term Care Assisted living facility Nursing Facility	Institution Care Person-centered care	Institutionali*ed Home for the aged Residential aged care facility Old people's home Retirement home Retirement facility
Residents	Patients Habitants Inhabitants	Elderly Aged Frail elderly Frailty Aging Older persons	