

Title: Development of the Quality of Life in Youth Services Scale (QOLYSS): content-related validity evidence based on adolescents' and expert reviewers' perspectives

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Abstract

Despite increased interest in the quality of life of younger populations, the quality of life of youngsters in vulnerable situations such as those in youth services remains under-researched. To gain insight into critical ingredients for understanding and enhancing the lives of these youngsters, appropriate assessment tools are needed. This study focuses on providing content-related validity evidence for the new Quality of Life in Youth Services Scale (QOLYSS) for adolescents in youth services. A sequential approach to item generation, refinement, and evaluation is presented. The initial item bank is devised by means of a thorough literature search and evaluated against findings from qualitative research among adolescents in youth services. In addition, a three-round international expert panel ($N=5$) is convened to align identified items to the adopted quality of life framework, and to provide evidence on domain representation and relevance. Last, input is collected from adolescents in youth services themselves. More specifically, 20 group discussions and 13 individual interview sessions are organized to support 21 adolescents in critically assessing the content of the item bank on level of relevance, clarity, and coverage. The expert panel resulted in a provisional scale of 262 unique items that, based on adolescents' input, is further reduced to a set of 88 items. Adolescents omitted items because of divergent reasons (e.g., content-overlap, self-evident character of the items, level of irrelevance). Explanatory qualitative information on the item selection process is provided. This study provides a detailed understanding of the content-related validity evidence of a new multidimensional quality of life scale. Moreover, it highlights the importance of acknowledging youngsters as critical partner in quality of life research and assessment.

Introduction

Quality of life has become a critical field of study and valued outcome in research and practice in different educational, health care, and social services (Moons et al. 2006; Schalock and Verdugo 2002). While the quality of life field has a strong tradition of working with adult populations and evaluations, research has only been drawing attention to the perspectives of the younger populations in society in the last few decades (Ben-Arieh et al. 2013; Casas 2016). This gap in research remains problematic, because the strength of quality of life lies in the fact that it taps into the subjective experiences of individuals involved (De Maeyer et al. 2011; Schalock et al. 2020). Now more than ever, the voices of youngsters themselves are considered a powerful catalyst for change. As such, it is pivotal for quality of life research and practice to focus on ways to discover and to amplify the voices and perspectives of youngsters in youth services (Knorth et al. 2014). In doing so, this approach can serve as a vehicle for social change and breaking down barriers that perpetuate prevailing dominant attitudes to (young) people living in vulnerable situations (De Maeyer et al. 2017).

This article focuses on the concept of quality of life among adolescents (12 to 18 years old) in youth care in Flanders, the northern part of Belgium. The term “youth care” is used to describe a diverse field of professional practice with a specific concern for promoting and enhancing positive development and well-being of youth and families in specific contexts. Youth care facilities range from various kinds of ambulatory services, home-based support interventions, to both short and long-term intensive residential care within, for example, mental health, juvenile justice, education and child welfare (Ungar et al. 2014). Young people in care in this study represent a broad group of youngsters in both the judicial (i.e. forced) and voluntary youth care system. These youth are in care because of divergent problematic living situations (e.g., difficulties in the relationship between youth and parents or guardian, loss of connectedness with school, drug use, truancy, aggression, emotional and behavioral disorders, etc.) or because they have been charged with a criminal offense (e.g., fighting, burglary, etc.).

Although it is indisputable that young people in care and after they leave care may experience a cluster of significant and complex challenges in different life domains (Dixon 2008; Jozefiak and Kayed 2015; Stein 2006), many researchers have predominantly adopted a deficit-oriented lens through which to understand the lives of youngsters living in vulnerable situations (Brendtro and Larson 2004; Cabrera et al. 2012). From this perspective, scholarly work tends to hold a singular focus on identifying the things in life that (can) go wrong and to gain insight in individual and environmental markers that increase the

probability of or protect against negative outcomes (Benson et al. 2006). In addition, it is the responsibility of practice to ameliorate or fix the deficits. Aiming to avoid difficulties in life is in itself not problematic, but this perspective is often underpinned by the notion of “youth as a problem”, a decontextualized generalization of young people as “pathological”, incapable, troubling, or even lost causes (Bertoni 2015; Finn 2001; Sukarieh and Tannock 2011). By asserting such a negative view, the actions, feelings and experiences of youngsters in care will inevitably be interpreted and understood solely from a pathological framework (Grant and Cadell 2009). Throughout the years, child well-being research has pointed out the limitations of a sole focus on risk factors or negative behaviors, and emphasized the need for an approach that covers positive well-being, things in life that youngsters value, their interests and capacities (Ben-Arieh 2008; Casas 2016; Lippman et al. 2011)

In order to ascertain the needs, priorities, wishes, etc., of youngsters starting from a positive viewpoint, practitioners can use quality of life assessment tools that are based on a specific validated theoretical and measurement framework (Claes et al. 2010). This direct way of collecting information from a first-person perspective provides a frame to look at the whole individual and to unveil various important ingredients about youngsters' life – starting from their own perspectives (Brown and Brown 2003). One theoretical framework of quality of life that has gained a lot of momentum in the past years, is the eight-domain model by Schalock and Verdugo (2002). This framework is adopted in this study, because it has received abundant scientific interest (in terms of conceptualization, measurement, validation and implementation) in different research areas such as education, elderly, mental health, residential youth care, addiction, and intellectual, developmental, physical, and sensorial disabilities (De Maeyer et al. 2011; Gómez, Peña et al. 2016; Gómez et al. 2019; Lombardi et al. 2016; Swerts et al. 2019) and it is also one of the most commonly reported in the field of youth care in Flanders (Swerts et al. 2019). This model describes quality of life as a multidimensional construct, comprising eight domains (i.e., personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, material well-being, and physical well-being) that are influenced by personal characteristics and environmental factors (Schalock et al. 2011). These core life domains are the same for all people but show individual and cultural variability with regard to their value and importance (Jenaro et al. 2005; Schalock and Verdugo 2002; Van Hecke et al. 2018). Previous research (Swerts et al., 2019) targeting this premise found positive results regarding the applicability and relevance of this framework to adolescents in out-of-home care, from the perspectives of youngsters themselves.

To the extent of our knowledge, only two scales based on this framework have been developed for use among adolescents: (1) the Personal Outcomes Scale (POS; van Loon et al. 2008), a self- and proxy report scale for quality of life evaluations among adults with intellectual disabilities, that was adapted to children and adolescents with intellectual disabilities (Claes et al. 2014); and (2) the KidsLife Scale (Gómez, Alcedo et al. 2016; Gómez et al. 2020, in press), a quality of life scale for children and adolescents with intellectual disabilities that relies on reports from third-party respondents. While both scales have been thoroughly investigated in the last years (Arias et al. 2018; Croce et al. 2014; Simões and Ribeiro 2018; Stone et al. 2020), they are specifically developed for use with (young) people with intellectual and developmental disabilities. While the eight quality of life domains are relevant to all people (Cummins 2005; Schalock and Verdugo 2002), domain-specific indicators that operationalize the core domains must be appropriate for the population under study (Fernández et al. 2018; Gómez et al. 2015). To better understand the quality of life of adolescents in youth services and to provide the field with an instrument with adequate evidence of reliability and validity to assess the quality of life of these youngsters, the new Quality of Life in Youth Services Scale (QOLYSS) was developed.

A minimum standard in the development of a person-centered outcome measure is that it is based upon a sound conceptual framework. This model must then be operationalized via a thoroughly conducted item development process involving various sources (Magasi et al. 2012). In doing so, it is crucial to meticulously document qualitative and quantitative evidence supporting its content validity (Reeve et al. 2013). Before being able to evaluate any score-based assumptions of a new measure, critically examining the instrument and its constituent items is considered central to the instrument development process (Brod et al. 2009). Sireci (1998) describes four elements of test quality that should be considered: domain definition, domain representation, domain relevance, and appropriateness of the test development process. In this paper, a sequence of consecutive stages of the instrument development process, divided into two studies, is described to provide this content-related validity evidence for the QOLYSS: (1) the first study involves developing the initial item bank and convening an expert panel to align the identified items to the eight-domain quality of life framework; (2) the second study focuses on the process in which adolescents in youth care were asked to critically assess all items on relevance, clarity, and coverage of the domains.

Study 1: Initial item bank development and content-related validity evidence based on expert reviewer judgments

A crucial first step in the development of a quality of life instrument is devising the initial item pool. While it is important to have a large pool of items, one should ensure that the set does not become impossible to administer (DeVellis 2017) but at the same time has sufficient content coverage. To enhance adequate content coverage, potential items were identified by means of an extensive and thorough review of the literature on quality of life instruments among adolescents. A large pool of 1056 items was extracted from the literature.

The best practice of item generation is to combine deductive (top-down) and inductive (exploratory qualitative design) methods (Boateng et al., 2018). In the construction of the QOLYSS, the initial item bank was generated via a deductive approach or top-down classification through a comprehensive literature search of existing assessment scales for adolescent quality of life. We identified various quality of life assessment tools for use among adolescent populations, such as the Kidscreen (Ravens-Sieberer et al., 2005), KidsLife (Gómez, Alcedo et al. 2016), Multidimensional Student Life Satisfaction Scale – adolescent version (Gilligan & Huebner, 2007), Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott et al., 2006), POS (van Loon et al., 2008) and Quality of Student Life Questionnaire (Keith & Schalock, 1995).

To provide a workable structure to initiate the item reduction process, the first author (C.S.) assigned each item to one of the eight quality of life domains or to a residual category in case of uncertainty. Duplicate items and potentially redundant items (i.e., construct-irrelevant items; items with content-similarities) were then independently identified by and discussed between the first author and another member of the broader research group. In case of disagreement in the discussion on items with content-wise resemblance, items were presented to a third member of the research group. This process resulted in a provisional item pool containing 264 unique items. The initial inventory of items was then compared to data we collected in a previous small-scale exploratory study of the perspectives on quality of life among youngsters in youth care in Flanders, in which a total of 45 adolescents between 12 and 18 years participated (De Wolf, 2019; Swerts et al., 2019). The aim was to investigate whether some important components of adolescent quality of life were missing according to the perspectives of

youngsters in youth are themselves. Given the comprehensiveness of the initial item bank, no additional items were added.

The next step focused on item refinement and creating a uniform set of items. To do so, the item pool was reviewed against a number of criteria relating to the interpretability of the items (Streiner et al. 2015): items should (1) be simple and as short as possible, (2) not be double-barreled (i.e., only address one issue), (3) use language familiar to the intended population (i.e., no jargon), (4) not be leading questions, (5) should be positively worded, and (6) allow responses on a six-point rating agreement scale. This initial item bank formed the basis for further evaluation by the international expert panel.

Methods

Participants

The item bank was reviewed and commented by an international expert panel, comprising a team of five experts from three different countries (i.e., Belgium, The Netherlands, and Spain) with significant expertise in the concept of quality of life. Four experts had in-depth research experience on the concept of quality of life in vulnerable populations and one expert had years of experience in implementing the framework into daily practice. Four experts also had substantial experience in research among children and adolescents in care, and two had been involved in previous projects focusing on (quality of life) scale development. The task of the expert panel was to reach consensus on the alignment of the items to the eight-domain quality of life framework and to provide evidence on domain representation and relevance.

Procedure

An Excel-file containing a randomized overview of the 264 items was sent via e-mail to the experts. Experts first received detailed information on the purpose of the expert panel and were presented with specific instructions for each of the rounds. For the first round, the experts were asked to read each of the 264 items and to assign them to the domain it best fits. The eight domains were supplemented with a 'residual' category in case of uncertainty about the classification of an item. In addition, experts were asked to highlight potentially redundant (e.g., irrelevant) and vaguely formulated items. In this round, items were retained if the majority of experts (4 out of 5) agreed that a particular item was associated with a specific domain. Items that did not reach 80% agreement level, would be

presented again in the next round. In addition, a detailed log was kept of the feedback from the experts. In the second round, each expert received a document with the anonymized results of the other experts for the remaining items, with their own responses marked in color. Each item was supplemented with the overall level of agreement in percentages, and qualitative information on why experts decided to assign an item to a specific domain. They were then asked to review their responses, taking into consideration the opinions of the other experts, and to indicate whether they would like to change or maintain their initial response. Experts were also encouraged to write down why they did (not) reconsider their earlier response. In the third round, experts were again presented with the remaining items and were encouraged to further discuss their earlier responses and the responses of the other experts. In addition, they were presented with the suggestions from experts to remove or reformulate certain items.

Results

After the first round, $\geq 80\%$ agreement was reached for 194 (73.5 %) items. This set was supplemented with an additional 29 items as a result of the second round. After three rounds, full agreement between the five experts was reached on 129 items (48.9%), 80% agreement on 121 items (45.8%), and 60% on 14 items (5.3%). Three items were eliminated because experts did not reach consensus on the domain these were applicable to. For example, the item 'I feel full of energy' was removed from the pool, because there was no agreement on whether this statement applied to the domain emotional well-being or physical well-being. In addition, one item was considered to be double-barreled: the statement 'I worry about being hurt or in pain' was split in two separate items, because all experts agreed that it tapped into a physical ('being in pain') and an emotional ('being hurt') component of well-being. Furthermore, one item ('My wishes are unrealizable') was reformulated ('I can realize my wishes').

The expert panel resulted in a pool of 262 unique items that have been aligned to the eight-domain framework. This item pool was then translated to Dutch, independently, by two members of the research group. In case of disagreement, the translated item was discussed with a third member of the research group. In addition, an independent quality control was conducted by an academic with a proficient level of English.

Study 2: content-related validity evidence based on adolescent judgements

Methods

Participants

A purposive heterogeneous group of youngsters was recruited in residential, home-based, and ambulatory facilities in Flanders. To do so, coordinators in organizations received information about the purpose of the study and were asked to act as intermediaries when the organization granted permission to participate in the research. To be eligible, youngsters had to be (a) in care, (b) between 12 and 18 years old, and (c) able to communicate in Dutch, but Dutch did not have to be their native language. Residential organizations were services providing long-term support to youth in vulnerable situations ($n = 10$) or providing specialized long-term support to youth with emotional and behavioral disorders ($n = 7$). Ambulatory services were services providing structured time-out or daytime activity programs ($n = 3$), or low-threshold support to children and adolescents in vulnerable situations ($n = 1$). Initially, 21 adolescents (of which 13 boys) between 12 and 17 years old ($M = 15$; $SD = 1.52$) were involved in this phase. The age at which they had been placed in care for the first time ranged from 3 to 14 years, and the number of previous placements ranged from 0 to 3. One adolescent withdrew from participation after one group session. The reason for this was that she was about to turn eighteen and she felt ready to leave care and live on her own without any professional support.

Procedure

This study was approved by all organizations involved in the project and by the Ethics Committee of the Faculty of Psychology and Educational Sciences at Ghent University, in accordance with internationally accepted criteria for research (2015/78). Adolescents received both oral and written information about the purpose of the study, and written informed consent was obtained prior to data collection. Respondents' parents or guardians were informed about the project by direct support staff, and none of the parental figures refused participation of the child. Adolescents received a voucher worth €10 for a local convenience store as compensation for their time invested.

Instruments

In the process of instrument development, individual interviews and focus groups are two dominant qualitative research methods used to ensure the instrument content aligns with the experiences and opinions of the people it focuses on. The research group initially considered to rely on

focus groups, as this qualitative method has been found appropriate to develop an understanding of children and adolescents their view and ideas on life (Skjerning et al. 2014; Swerts et al. 2019). However, a number of individual interviews were also conducted because some adolescents: (1) expressed a desire to participate, but only if they could do it individually; or (2) were not able to participate in the upcoming sessions of the group discussion because they were relocated to another organization (e.g., because of a mandatory time-out).

All interviews were conducted by one member of the research group. For each focus group, the same two researchers were present. One took on the role of moderator and led the group discussions, the second researcher made observations and supported the moderator. Both research members had previous experience in working with adolescents in youth care and did not know the respondents prior to the focus groups and interviews.

In the first group discussion and interview, the purpose and ethical aspects of the study (e.g., voluntary participation, right to refrain from participation at any moment with explanation, etc.) were explained. The sessions were audio-taped and were transcribed verbatim. Comments made by respondents for each of the items were documented in a separate file to provide an overview of underlying reasons regarding the relevance, clarity and coverage of the item pool.

The adolescents were asked through a dialogical approach to review all unique items ($N = 262$) resulting from the expert panel on relevance, clarity, and coverage of the different domains. Respondents were first presented with an overview of the quality of life domains in the form of visualizations and were provided with basic information about the main content of each domain. They were then asked which of the domains they wanted to discuss first. When a domain was chosen, all items pertaining to this domain were put on the table. Three large papers were put on the wall: (1) important items, (2) not important and (3) uncertain. Respondents were asked to read all items aloud one-by-one and were asked whether items were important to the quality of life of adolescents in youth services. In so doing, a discussion was held on why specific items were (not) important or unclear, and on the terminology used (i.e., whether it was appropriate for adolescents). In addition, youngsters were explicitly asked to add new items to the existing pool if they felt that important and meaningful items were missing. By doing so, youngsters were involved in both the development of new items and the selection of previously developed items.

Table 1*Detailed overview of the sessions organized (N = 33) to evaluate the item pool*

	Session number	Youngsters present	Duration in minutes	Domains evaluated ^a	Number of items
Individual	1	#1	89	IR	56
	2	#1	257	SD; EW; R; MW; PW	135
	3	#1	144	SI; PD	71
Group	4	#2, #3	54	EW	40
	5	#2, #3	57	MW; PW	36
	6	#2, #3	59	SI; PD	71
	7	#2, #3	69	R	34
	8	#2, #3	72	IR; SD	81
Group	9	#4, #5, #6, #7	75	PD; SD	68
	10	#5, #6, #7	72	PW; MW	36
	11	#5, #6, #7	78	SI; RE	62
Group	12	#5, #6, #7	72	EW; IR	96
	13	#8, #9, #10	71	EW; R	74
	14	#8, #9, #10	112	IR; MW; PW; PD	135
	15	#8, #9, #10	58	SD; SI	53
	16	#11, #12, #13, #14	56	R	34
Group	17	#12, #13, #14	70	SD; PW; MW	61
	18	#12, #13, #14	52	IR	56
	19	#13, #14	75	EW; PD; SI	111
Individual	20	#11	36	SI; PW	44
Group	21	#11	27	SD; MW	45
	22	#15, #16, #17	62	IR	/ ^b
	23	#15, #16, #17	25	PW; MW	36
Individual	24	#16, #17	56	SI; PD	71
	25	#18	41	SD	25
Group	26	#18	37	MW; PW	36
	27	#19, #20, #21	77	SD; SI; MW	73
Individual	28	#19	75	IR; R; EW; PD; PW	189
Individual	29	#20	51	R	34
	30	#20	104	IR; PD; PW	115
	31	#20	23	EW	40
	32	#21	41	R	34
Individual	33	#21	57	IR	56

^aIR (interpersonal relations); SD (self-determination); EW (emotional well-being); R (rights); MW (material well-being); PW (physical well-being); SI (social inclusion); PD (personal development)

^bThe youngsters selected the domain IR to start with, but only succeeded to discuss a few items. The research team decided to not include any items discussed in this session, because the needs of the youngsters (related to emotional and behavioral disorders)) led the research team to redirect the session from discussing items to first get to know each other and build up a trust relation.

In total, 33 sessions (20 group discussions and 13 interviews) were organized between January 2019 and July 2019, with 2 to 5 sessions per youngster or group (see Table 1). Interviews and focus groups were conducted in a separate room at the respondents' organization or at their home (for one

adolescent). The median duration of the sessions was 65.5 minutes (range: 23min to 4h17min). The large variation in duration is the result of both the number of domains that were discussed in one session and the needs of youngsters. For example, one session lasted not more than 23 min, because it was the final interview and only one domain remained to be addressed. One session lasted more than four hours, because the level of motivation to discuss items was very high among this youngster. This interview, however, did not consist of an uninterrupted four-hour session. The interviewer never forced the youngster to continue, but adhered to his wish to continue the conversation. The interviewer created space for the youngster to discuss as much or little as he/she wanted and regular breaks were taken. With regard to the specific needs of youngsters, for example, in one focus group with youngsters with severe emotional and behavioural disorders (session 23), the youngsters managed to remain focused for only 25 minutes and expressed the desire to stop the session.

Results

In total, 13 adolescents evaluated the complete set of 262 items. The evaluation rates for the remaining youngsters were: 163 items (62.2%, $n = 1$), 151 items (57.6%, $n = 1$), 123 items (46.9%, $n = 1$), 107 items (40.8%, $n = 2$), 68 items (25.9%, $n = 1$), and 61 items (23.3%, $n = 1$). The different domains have a completion rate ranging from 61.9% ($n = 13$) for the domain *emotional well-being* to 95.2% ($n = 20$) for the domain *material well-being* (see Table 2).

Table 2

Completion rate of domains

Domain	Initial number of items	Adolescents completed evaluation (% of total)	Number of items retained	Level of agreement (\geq)
Interpersonal relations	56 items	15 (71.4%)	11	75%
Social inclusion	28 items	17 (81%)	11	50%
Rights	34 items	16 (76.2%)	14	75%
Personal development	43 items	16 (76.2%)	10	75%
Self-determination	25 items	18 (85.7%)	10	75%
Material well-being	20 items	20 (95.2%)	11	65%
Physical well-being	16 items	19 (90.5%)	9	50%
Emotional well-being	40 items	13 (61.9%)	12	75%
Total	262 items		88	

An analysis of the qualitative approach with adolescents was conducted by calculating the level of agreement for each item in respect to the total number of youngsters that evaluated the respective item. In the first analysis, an initial cut-off rate of 75% was used. This resulted in 72 items across eight domains. However, the research team decided to aim at least at 10 to 12 items per domain, with a floor percentage to retain items set at 50%. This process resulted in a selection of 88 items across eight domains (see Table 2). An overview of the QOLYSS items can be found in annex 1.

Qualitative analysis further revealed a number of reasons why items were omitted by adolescents. First, some items were considered **irrelevant or not as relevant compared to others**. For example, in the domain interpersonal relations, the item 'Being satisfied with the number of friends' was considered not relevant or less relevant than the item on 'Overall satisfaction with friends'. As one adolescent reported, 'The more friends you have, it could be important, you know. It could mean you get more support from those people, so more friends could be fun ... But actually, no, you could also have like three friends that do so much more than twenty.'

Second, there were several items that inquired about the **same core issue but in various specific settings**, which –according to respondents– could decrease adolescents' motivation to respond. For example, almost all youth agreed that one item on safety was better than asking them a wide array of questions on safety in different contexts (e.g., 'I feel safe in my neighborhood', 'I feel safe at school', 'I feel safe at street', etc.). Similarly, respondents preferred that the scale would integrate one item on how they are feeling instead of using numerous items pertaining to emotions (e.g., 'I feel happy', 'I feel sad', 'I feel anxious', etc.).

Third, in case of high content-relatedness between items, respondents focused on **prioritizing the relevance** of items. For example, adolescents discussed the similarities and differences between the items 'Getting along with teachers' and 'Feeling understood by teachers'. There were a few adolescents stating that teachers are just there 'to teach' and not to have a connection with. The majority, however, prioritized getting along with teachers over being understood by them. As one adolescent stated, 'I prefer to get along with teachers, then having them understand me. I don't expect them to understand me. I don't expect that, because I also have difficulties understanding other people. I can hardly image how it must be for people who are in a different situation that I am. And I have experienced a lot of situations in my life, such as divorced parents, being place out-of-home'

Fourth, the **self-evident character** of some items was emphasized by respondents. While a number of adolescents considered ‘Having reliable friends’ of great importance, this item was omitted from the scale because of the reason that if people are not reliable, they are not considered friends.

In order to enhance the understanding of the item selection procedure, Table 3 provides an overview of several qualitative descriptions of adolescents’ reasons to retain items.

Table 3

Qualitative descriptions regarding the relevance of retained items

Examples of retained items	Quotes detailing item relevance
‘I get the chance to fix mistakes I make’	‘Ooh, definitely man! If I wouldn’t get that opportunity, oh man, that would be so serious. You understand? It’s always so annoying when people act like that, like you make one mistake ... Okay, not everything I have done in my life was good ... Okay, sometimes you deserve some kind of punishment, but still, you always deserve to get a couple of chances in life.’
‘Friends see me as someone they can rely upon’	‘I love it when my friends consider me as someone they can trust. I love to be their chosen family ... Friends are something you chose and if you can give that feeling [of being reliable] to your friends ... that is like being seen as family.’
‘I have enough opportunities to see my friends’	‘It’s very important. In an organization, but also when you’re staying at home ... you know, it’s really annoying. Sometimes you want to, for once, not that it has to be like every week, but just once a month that your parents or direct support staff would say that you can go to your friends, but without specifying an hour you have to be back. Just saying you must be wise, don’t do anything stupid, but just for once having that freedom.’
‘I am involved in decisions made about my life’	‘Making my own decisions is really important, because I don’t want people bossing me around. But I don’t want to decide about everything. For example, I have a friend, but she’s actually a <i>bad</i> friend. My parents would say I wouldn’t be allowed to see her. But if I would decide everything on my own, I would hang out with her. But then, I would probably go down the wrong path in life and I don’t want that.’
‘I am able to do things independently’	‘I want to be as independent from others as possible, because I want to move on with my life without them [direct support staff] because eventually they would be gone. You get it? Just, doing things without the help of others ... you can do that, but first you need help to do so.’
‘I am satisfied with my neighborhood’	‘It’s hard to get to know your neighbors. On the one hand, I think is very important that you know the people in your neighborhood ... At my place, I knew who my next-door neighbor was, but we didn’t get along ... But here [residential organization], it’s really hard. It’s not like you’re able to go with the entire group saying ‘Hi, we are your neighbors’ ... A lot of people still have prejudices about young people in care.’
‘I am worried about getting into debt’	‘Not at this moment, but maybe in a few weeks when I will get my own debit card. I really think I will not be able to use it wisely.’

‘I have enough allowance (to save, buy things I need, etc.)’	‘It is not the most important thing in life, but until a certain level. It is important you’re able to buy some things you need or do things you like to do, to have a normal life.’
‘I feel useful to others’	‘That you play a part in someone’s life... This question is about the fact they you think it’s that you are considered important in the lives of some people. Not just family or friends, but also just others.’
‘I feel good about my future’	‘I am not sure what the future holds for me. In fact, I find the future even frightening, because I don’t know what it’s going to bring. This is one of the things that frightens me. What will the future bring? Where am I in ten years? ... My future? That’s the time after high school, when I will move out of this place [residential organization]. But that’s also on short term, if all goes well I will be gone from this place in a year. A year, where will I be in a year?’
‘I am proud of the things I do’	‘Its important to be proud in life, to be proud on the good things, yeah. But on the bad things, no.’
‘I feel respected when I say no’	‘You shouldn’t always say no, you know? But if it’s about something in life you really need to dare to say no, then it’s important. But that depends from situation to situation.’; ‘When you say no, others should respect that. I am not talking about stupid things; this question really focuses on serious things in life.’

Discussion

This article presents the initial development process of the QOLYSS, a new scale –based on the framework by Schalock and Verdugo (2002)– to assess the quality of life of adolescents in youth care. More specifically, this study adopted a combination of methods to provide evidence on the content-related validity, which is a critical first step to ensure that the instrument includes content that is relevant to what is intended to be measured and that adequately represents the intended concepts of interests (Fayer and Machin 2007; Streiner et al. 2015). Whilst an initial item bank was carefully designed by building upon previous insights from quality of life research, outsider knowledge (i.e., international expert panel) was used to obtain evidence on domain representation and relevance. Last, but most importantly, direct youth input (insider knowledge) provided in-depth qualitative evidence regarding the scale content. This sequential process led to the development of an initial field test version comprising 88 items.

This study emphasized the value of youngsters’ perspectives in the scale development process. Because the concept taps into the subjective experiences of individuals concerned, gaining direct appraisal and feedback from respondents from the intended population is crucial to a scientifically sound quality of life instrument development process (Brod et al. 2009). Over the last decade, qualitative

research designs have become more common in quality of life research to identify the views and opinions of children and adolescents themselves regarding their life (Casas 2011; Chavez et al. 2012; Fattore et al. 2007; Swerts et al. 2019; Van Hecke et al. 2019]. These designs are often used to inductively devise items to supplement the set of experts' or adults' opinions. In this study, a collaboration was set up with a heterogeneous group of adolescents, in terms of age, gender, and type of service (residential, home-based, and ambulatory), to critically review and assess the initial item pool on importance, relevance, clarity and comprehensiveness. In doing so, validity evidence on test content from adolescents' perspectives (insider knowledge) is provided. While a number of items have been omitted from the scale because of various concerns (e.g., self-evident character), it is noteworthy that these items can also yield valuable information about the life of adolescents in care. The youngsters, however, further stressed the importance of carefully choosing items, because having too many (similar) items or items that youngsters consider irrelevant to their lives, would evoke a sense of burden among future respondents and decrease their willingness to complete the scale.

This study further highlights the importance of providing youngsters the opportunity to express themselves in their own words and at their own pace within research practices. However, when involving youngsters in research it is not their individual responsibility to voice their opinion. It is important that an inclusive and safe space is created where all youngsters involved are facilitated to express their own views freely, and where their views are listened to and acted upon accordingly (Lundy 2007). When paraphrasing one adolescent, in order for young people to be actively invested in research where they are asked to discuss details about their life and what they value, they need to know and feel they are not going to be reprimanded, punished or belittled, and thus have the feeling they can say anything they want.

We ensured that the research phase of documenting qualitative evidence was adequately adapted to the pace of youngsters. We aimed to reduce time constraints as much as possible, because not having enough time should never be the primary reason adolescent input is not collected properly or thoroughly. Therefore, qualitative information was collected over the course of several months and via numerous gatherings at times and locations that were most convenient to youngsters. This made it possible to invest in a real partnership and to form a connection of trust. In doing so, youngsters were taken seriously, their voices were given due weight, and they were not treated as a token to "prove" a supposedly just approach to youth involvement in research. Furthermore, the approach adopted in this

study emphasizes youngsters as principle source of information when studying the topic of adolescent quality of life. This study started from a profound belief in the voice and role of youngsters, and subsequently also placed them central in the decision-making process on the final item bank.

Regardless of the strengths of this study, there are limitations that must be taken into consideration. Because of the size of the initial item bank, not all youngsters were able to discuss all items in the eight domains. Youngsters were free in deciding whether they wanted to continue with completing the evaluation or not. Eventually, 13 adolescents were willing to complete all items. Furthermore, it should be noted that not all participants were always able to fully articulate the reason why they thought certain items were more important than others. This appeared to be the case for some adolescents receiving specialized long-term support in a service for youth with emotional and behavioral disorders. In addition, it is argued that in focus group discussions, dominant talkers could more easily voice their opinion and in doing so overshadow shy participants and reflective thinkers (Krueger and Casey 2015). To counter these situations, moderators were chosen who had previous experience in conducting focus groups and in working with youngsters in youth care. As such, the moderators encouraged participants to actively participate and discuss each other's contributions in the discussion. Moreover, no in-depth comparisons were made between youngsters who are supported in residential and out-patient settings. While this was beyond the scope of the study, a valuable pathway for future research could be to examine potential differences in youth care settings. Also, no additional information was retrieved from collateral sources such as parents or direct support staff. While some may argue that this is a limitation of the study, it is important to emphasize that adult perspectives are not the same as youngsters' perspectives (Casas 2016). An important question to consider when making decisions regarding information sources is how accurate other people can respond on behalf the person, especially with regard to the quality of their lives –which is in essence a deeply personal and subjective phenomenon. The best and primary source of information to rely upon when studying adolescent quality of life remains or should remain youngsters' own perspectives (Ben-Arieh 2005).

To conclude, over the last decade, the concept of quality of life has gained considerable momentum in research and practice as a positive and less stigmatizing way to understand the lives of youngsters living in vulnerable situations. To support this understanding, a thorough and comprehensive quality of life assessment can help to discover (new) information regarding what youngsters themselves deem important in their life. It can facilitate generating more appropriate and personally valued goals,

determine strengths, needs and wishes from a person-driven perspective (Brown and Brown 2003). This kind of research is crucial as this information can further be used in daily practice to develop and implement individualized support, and to conduct outcome-based evaluations in organizations, which in turn contributes to improving the quality of life of youngsters in care (Schalock et al. 2008). Before the QOLYSS can be used for these purposes, it is important to gain further insights in the overall applicability of the scale and to check for potential issues of response error and issues such as respondent burden (Fayer and Machin 2007). Therefore, the scale will first be pre-tested in a small group of youngsters that represent the target population. The next step in the process involves a large scale field-test and subsequent psychometric evaluation in Flanders to document additional quantitative evidence to confirm the structure of the multidimensional scale and to extend the results from the qualitative research items (Magasi et al. 2012).

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