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Applicability of a Tool for Comprehensive Pediatric Assessments: The Expanded Guide for Monitoring Child Development

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Abstract

Background: Tools that provide comprehensive information about children and families without increasing face-to-face time during healthcare encounters are critically needed in clinical practice. We aimed to examine the applicability of such a tool, an expanded version of the international Guide for Monitoring Child Development (Expanded GMCD), a largely open-ended written questionnaire that incorporates the World Health Organization International Classification of Functioning, Disability and Health and Nurturing Care frameworks.

Methods: Parents of children attending Ankara University Developmental Pediatrics Division, Turkey, were asked to complete the Expanded GMCD and bring it back for their first developmental assessment. Child and family related factors associated with completion rates were ascertained using multivariate analyses.

Results: Of 494 eligible children, 480 (97%) comprised the study sample. Most were boys (57%); median age was 17.0 (IQR: 9.0-27.0) months. All four domains of the Expanded GMCD were completed by 78% of the families; 87% completed at least three and 92% at least two domains. The domain "child functioning" was completed by 94%; "activities and participation," "health" and "nurturing care environment" domains were completed by > 80% of families. Families provided comprehensive information on the Expanded GMCD: developmental difficulties (87%), chronic health conditions (60%) in their children; as well as environmental risk factors including stigmatization (27%), maternal depression (20%), financial difficulties (17%) and inadequate social support (14%). Families of children aged \leq 6 months were more likely not to fully complete the Expanded GMCD (OR: 2.24; 95% CI: 1.25-3.72); other child or family related factors were not associated with completion.

Conclusion: The applicability of the Expanded GMCD in this study implies its potential for applicability in other clinical settings. The use of the free-of-charge, readily available Expanded GMCD may address the urgent need of child healthcare providers in obtaining comprehensive information about children and families without lengthening face-to-face time.

Keywords: Assessment tool, Child development, International Classification of Functioning, Disability and Health (ICF), Nurturing care, Open-ended questionnaire, Special needs

Background

Obtaining comprehensive information on the biopsychosocial aspects of health, development and illness is known to be a crucial part of delivering health care [1]. There are still major gaps, however, in obtaining such information for children, as child healthcare providers even in high income countries encounter constraints such as insufficient time devoted to health care visits, inadequate training on comprehensive history taking and paucity of compact tools that encompass all components of a comprehensive pediatric history [2]. The coronavirus disease 19 (COVID-19) pandemic has brought novel challenges by adding inordinate stress on health systems and further jeopardizing the time that needs to be spent during face-to-face history taking to obtain holistic bio psychosocial information [3]. Tools that provide comprehensive information about children and their families, that require minimal training for the workforce and that do not increase face-to-face time during health care encounters are needed more urgently now than ever before.

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The comprehensive assessment of children's health and development is guided by two frameworks of the World Health Organization (WHO): the International Classification of Functioning, Disability and Health (ICF) [4] and Nurturing Care Framework [5]. Both of these frameworks are derived from the long established biopsychosocial model [6] and family-centered care [7], cornerstones of child healthcare delivery. The ICF, available for nearly two decades, has been the recommended framework for the assessment of child health, development, illness and disability [8]. The ICF includes "health conditions," "body structures and functions," "activities and participation," "environmental (contextual)" and "personal" factors. The complexity of the ICF coding has been cited as a limiting factor on the clinical use of ICF [9].

The WHO Nurturing Care Framework (NCF) has been launched in 2018 with the aim of providing guidance in monitoring and supporting the optimal development of young children within healthcare systems [5]. International organizations such as the WHO increasingly prioritize the promotion of optimal child health and development [10]. This is due to the rapid development of the brain during early childhood, the life-span influences of the contextual environment, and the high prevalence of suboptimal health and development during early childhood [11]. The NCF includes "good health," "adequate nutrition," "responsive caregiving," "opportunities for early learning," and "security and safety." The NCF has been recently launched and to date, research on tools that incorporate all components of the NCF into pediatric assessments, has not been published.

A tool which has been grounded in the two WHO frameworks ICF and NCF as well as bioecological theory and family-centered care is the international Guide for Monitoring Child Development (GMCD) [12, 13]. The GMCD is a brief ten-minute open-ended interview with families which enables service providers to assess the child's functioning in the domains expressive and receptive language, gross and fine motor, play, relating and self-help and identify developmental delays if present [12]. Health care providers using the GMCD can also identify psychosocial risk factors, child and family strengths and needs and can use the GMCD to provide individualized early interventions [14]. The GMCD has been standardized and validated in four diverse countries, Argentina, India, South Africa and Turkey [12, 13] and has been rated highly among tools that can be used internationally [15, 16]. Clinicians from over 30 countries have been trained in using the GMCD and national trainers exist in 13 countries [14, 17]. The GMCD developers, Ertem et al. have constructed the Expanded GMCD by distilling, incorporating and bridging seminal techniques of the GMCD, and all components of the ICF and NCF. So as not to increase face-to-face time, the Expanded GMCD was constructed as a written fourth grade reading level questionnaire to be completed by families in their homes or in waiting rooms for outpatients and during hospitalization for inpatients so as to save time during face-to-face contacts. Examples of the Expanded GMCD questions are shown in figure 1. The

Exp-GMCD domains and examples of questions	Needs support
Developmental functioning	
Expressive language. How does your child let you know when she wants something? Please	
write down examples of sounds, words, hands or body gestures she uses.	
Activities and participation	10
Please check your child's regular activities, write number of days per week she does these.	
☐ Plays with other children: ☐ Visits relatives or friends:	
☐ Goes to the playground: ☐ Plays with a pet animal:	
□ Plays in nature:	
☐ Goes to preschool:	
Environmental factors (Nurturing Care framework is incorporated to this domain)	
As caregivers, what do you do to support your child's learning and development?	
What does mother do?	
What does father do?	
What do other family members do?	
Psychosocial risks. Sometimes caregivers may have a lot going on. They may find it hard to	
support their child's development. Please check all difficulties we listed below that are true	
for you or your family. Explain each one you checked.	
☐ Unemployment, financial problems:	
☐ Mother feeling down, depressed:	
☐ Father feeling down, depressed:	
☐ Marital problems, divorce:	
☐ Family violence:	
☐ Problems with other siblings:	
☐ There is an ill person in the family:	
☐ Not getting enough support from friends and relatives:	
☐ Other difficulties:	
Services. Did your child receive services to support her learning, development, movement?	
□ No □ Yes, check below all services received, write their duration.	
☐ Physical therapy/Rehabilitationmonths ☐ Occupational therapymonths	
☐ Early interventionmonths ☐ Special educationmonths	
☐ Name any other special services and write duration:	
Stigma. Sometimes caregivers may experience prejudices, stigmatization or negative	
attitudes of others because of their child's situation. These attitudes may affect your child,	
hurt your feelings, or make your life harder. Please explain any such situations:	

Figure 1: Examples of Expanded GMCD* questions for each domain. *GMCD: Guide for Monitoring Child Development.

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Expanded GMCD takes approximately 30 minutes for the families to complete. The open-ended question structure of the GMCD was retained in the Expanded GMCD to allow for richness of information and unrestricted descriptions and to capitalize on the most important benefit of open-ended questions- finding more than what is anticipated, particularly related to concerns, observations, problem-solving strategies as well as hopes and fears of respondents [18]. As can be seen in figure 1, structured checklist components also exist. Child health care providers can read the completed Expanded GMCD in five minutes and learn details about the current and prior health conditions, functioning, participation in life and psychosocial context of the child and family, their strengths, needs and unmet needs. They can then partner with the family, elicit further history if needed, and conduct the face-to-face components of the assessment such as a physical examination and developmental observations. The Expanded GMCD is a free-of-charge tool with a brief online training program for service providers around the world. It can be used for all children, particularly those children with chronic problems, developmental difficulties and special needs. The tool can be used by community health care providers, family physicians, pediatric subspecialists, pediatric surgeons, child and adolescent psychiatrists as well as clinicians from allied disciplines such as psychologists, social workers, occupational and physical therapists, teachers, early intervention specialists and other service providers. The Expanded GMCD can be combined with other tools for medical and developmental assessments but also can be used as a stand-alone instrument.

The Expanded GMCD development and validation study included chronically ill-hospitalized children whose mothers completed the Expanded GMCD during their hospital stay [19]. This study showed that the Expanded GMCD enabled coding of 95% of the ICF codes and was completed by nearly all mothers although 90% had less than high school education.

The applicability of the Expanded GMCD in an outpatient setting, which is how the majority of children receive health care, has not been established. The aim of this study, therefore, was to examine the applicability of the Expanded GMCD, specifically, to determine to which extent parents complete its domains before an outpatient assessment, and whether there are child or family related factors associated with completion rates.

Materials and Methods

Study design and participants

In this cross-sectional study, children aged 0-42 months, attending Ankara University Developmental-Behavioral Pediatrics Division (AUDPD) clinic over a twelve-month period starting 1st January 2016 were recruited. Children were included if they came for their first developmental assessment and their caregivers provided consent.

Procedures

The study followed the routine procedures of the AUDPD clinic. When they came to obtain an appointment, parents were given the printed Expanded GMCD and explained the following: as much as possible both parents or legal guardians of the child should complete the Expanded GMCD together; completion time is approximately 30 minutes; other family members or friends can assist in reading the questions and writing; detailed responses by parents to all questions are important; the Expanded GMCD must be brought back for the developmental assessment appointment. This information was also written on the Expanded GMCD. The first author (EOA) recorded the Expanded GMCD forms given out and brought back by the families and assessed which components of the tool were completed in writing by the parents using a checklist developed for the purposes of this study. The Ethics Committee of the Ankara University School of Medicine approved the study.

Measures

All components of the ICF ("health conditions," "body structures and functioning," "activities of daily living and participation in life," "environmental" and "personal factors") and the NCF included in the Expanded GMCD were used in this study. To enable content flow, questions on components of the NCF ("adequate nutrition," "responsive caregiving," "opportunities for early learning," and "security and safety") were incorporated into the "environmental" domain of the GMCD. The ICF component "personal factors" (temperament, interests, and dreams of the child, aspirations of the family for themselves and the child) integrated into "body structures and functioning" resulting in four Expanded GMCD domains to be analyzed. Figure 1 shows examples of questions for each domain.

The diagnoses of the children were provided by developmental pediatricians at AUDPD who conducted a comprehensive developmental assessment based on principles of bioecological theory, biopsychosocial model, ICF, transdisciplinary, and family-centered care. The clinicians read the answers that had been written by the parents on the Expanded GMCD. They elicited further history when needed, observed child-caregiver play and conducted a physical examination. During the physical examination, appearance affecting conditions [20] such as tracheostomy, colostomy, ventriculoperitoneal shunt were also recorded as components of the "body structures" domain. Standardized developmental assessment tools were used according to the child's needs and included the GMCD, Bayley Scales of Infant and Toddler Development Third Edition, Vineland Adaptive Behavior Scales Third Edition, and the Childhood Autism Rating Scale Second Edition (CARS-2). The diagnoses were based on the WHO International Classification of Diseases-10 criteria for chronic illnesses, cerebral palsy and genetic disorders; and the Diagnostic and Statistical Manual of Mental Disorders 5th Edition and CARS-2 criteria for autism spectrum disorder.

Statistical analyses

Descriptive statistics included frequencies for categorical data; means and standard deviations for normal distributions; and medians and interquartile ranges, otherwise. The four domains of the Expanded GMCD were scored "1" if every question on the domain was completed and "0" if not completed by the parents. The scores for each domain were added to comprise a total completion score ranging from a minimum of 1 to a maximum of 4. The total completion scores were then dichotomized as completion score = 4 and completion score < 4. This stringent cut-off for completion score was chosen so as to determine which families provided fully complete (completion score = 4) and less than fully complete (completion score < 4) information on the Expanded GMCD. Based on anecdotal observations, it was hypothesized that younger child age (families

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of younger children may know less about their child); lower maternal and paternal education (parents with lower education may have difficulties in written questions and responses) and having multiple children (caring for numerous children may distract parents from completion), may impede completion. Due to possibilities of gender inequality leading to reporting bias, we also examined whether completion rates were different for girls versus boys. First, bivariate analyses were conducted for categorical variables using Pearson Chi-square. Odds ratios for two groups were computed for girls versus boys, 0-6 months versus older, multiple children versus single and maternal or paternal education less than high school versus at least high school education. Next, multivariate logistic regression analysis was applied entering variables with odds ratio p values < 0.10 [21] to determine independent factors associated with the dependent variable (total completion score < 4). For statistical significance 95% confidence intervals (CIs) were used. Statistical analyses were done using IBM SPSS 20.0 (SPSS Inc., Chicago, IL, USA) package program.

Results

During the study period, 494 eligible children were given first appointments, and 14 (3%) did not return for their appointment. All 480 families coming for their appointment brought back the Expanded GMCD and comprised the study sample. The socio-demographic characteristics of children and their families are shown in table 1. Most children were boys (57%); the median age of the sample was 17.0 (IQR: 9.0-27.0) months. The median maternal and paternal ages were 31.0 (IQR: 27.0-35.0) and 34.0 (IQR: 30.0-38.0) years, respectively. Most mothers (68%) and fathers (76%) had completed at least high school education. Most families had multiple children (55%) and as per the Turkish healthcare system, all family members had health insurance.

Information provided by the caregivers on the Expanded GMCD is shown in table 2. Most of the children had chronic illness or congenital Table 1: Socio-demographic characteristics of the sample (N=480).

		n	%
Boys		272	56.7
Child age (months)	0-12	180	37.5
	13-24	152	31.7
	25-42	148	30.8
Maternal age (years)	< 20	8	1.7
	21-30	219	45.6
	> 30	253	52.7
Paternal age (years)	< 20	1	0.2
	21-30	130	27.1
	> 30	349	72.7
Maternal education	Less than high school	153	31.8
	High school	131	27.3
	Higher education	196	40.8
Paternal education	Less than high school	115	24.0
	High school	163	34.0
	Higher education	202	42.1
	Single child	217	45.2
Number of children	Multiple children	263	54.8

Table 2: Information provided by parents on the Expanded GMCD domains (N = 480).

	n	%
Health conditions		-
Chronic illnesses or congenital disorders	190	39.6
Prematurity and its complications	98	20.4
Autism spectrum disorder	33	6.9
Cerebral palsy	14	2.9
mpairments/delays in body structures and functioning		
Expressive or receptive language	265	55.2
Gross or fine movement	161	33.5
Cognitive development	151	31.5
Social-emotional development	79	16.5
Behavioral problems	63	13.1
Appearance affecting conditions (examples: gastrostomy, colostomy, tracheostomy, ventriculoperitoneal shunt)	40	8.3
Vision or hearing impairment	49	10.2
Activities and participation		
Child attends preschool	14	2.9
Child attends early intervention/special services	21	4.4
Risks in environmental factors including nurturing care		
Perceived stigma	128	26.7
Mother's feelings of depression	96	20.0
Unemployment, financial problems	81	16.9
Not getting enough support from friends and relatives	69	14.4
Father's feelings of depression	50	10.4
Marital problems/family violence	25	5.2

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disorders (40%); and 10% had autism or cerebral palsy. Comprehensive developmental assessments revealed that 87% had developmental delay in at least one developmental domain, and the rest of the sample had behavioral problems only. Parents reported limitations in activities and participation: most children (93%) did not attend nursery school, daycare or preschool or early intervention services. Approximately 27% of families reported perceived stigmatization, 20% reported feelings of depression in mothers and 10% in fathers; 17% reported unemployment or financial difficulties, 14% not getting enough support from friends and relatives, and 5% reported marital problems or family violence. Of 263 families with multiple children 29 (11%) reported social-emotional problems in siblings.

The proportions of families completing the Expanded GMCD domains are shown in table 3. Most families completed all four domains (78%); 87% completed at least three, and 92% completed at least two domains. The domain with the highest completion rate was "child functioning" (94%), the other three domains all had completion rates above 80%.

Table 4 shows the bivariate odds ratios of child and family related factors that were examined for their association with Expanded GMCD completion rates. Among these associations child's age<6 months, maternal education less than high school, and multiple children in the family had odds ratio p values < 0.10. Child sex, and paternal education both had odds ratio p values ≥ 0.10 . In the multiple logistic regression analysis (Table 4), child age less than 6 months was found to be the only statistically significant independent variable associated not fully Expanded GMCD completion rates. Families of children aged 0-6 months were 2.24 times more likely than families of older children to have completion scores < 4, therefore less full-completion rates.

Post-hoc analyses were conducted to determine whether there was a predilection for not completing a specific domain of the Expanded GMCD by families of children aged 0-6.months. The domains "health condition", "functioning", "activities and participation" and "environmental factors" were completed by 88%, 86%, 83%, 75% of families with children aged 0-6 months, respectively. Compared to families with older children, families with children aged 0-6 months were statistically significantly more likely not to fully complete "body structures and functioning" (OR: 4.28; 95% CI: 1.96-9.37); "activities and participation" (OR: 2.06; 95% CI: 1.07-3.96); and "environmental factors" (OR: 1.84; 95% CI: 1.06-3.22) domains. This association was not significant for the "health condition" domain (OR: 1.20; 95% CI: 0.59-2.44).

Discussion

This study demonstrates the applicability of the Expanded GMCD for young children attending a developmental pediatric clinic in Turkey. The Expanded GMCD provided information on health conditions, developmental functioning, activities and participation, and on the caregiving

Number of completed Expanded GMCD domains 372 77.5 All four domains At least three domains 415 86.5 442 At least two domains 92.1 Completed Expanded GMCD domains Body structures and functioning 452 94 2 430 Activities and participation 89.6 Health condition 428 89.2 Environmental factors (including nurturing care) 399 83.1

Table 3: Completion rates of the Expanded GMCD and its domains (N = 480).

Table 4: Bivariate and multivariate analyses of child and family related factors associated with Expanded GMCD* completion (N = 480).

	Prop	Proportions		Expanded GMCD completion score < 4				
	n	%	n	%	OR	95% CI	p value	
Bivariate analyzes	'							
Child related factors								
Girls	208	43.3	41	19.7	0.75	0.48-1.16	0.201	
Boys	272	56.7	67	24.6				
Age ≤ 6 months	89	18.5	31	34.8	2.18	1.31-3.60	0.002	
Age > 6 months	391	81.5	77	19.7				
Family related factors								
Maternal education < high school	153	31.8	42	27.5	1.49	0.95-2.33	0.076	
Maternal education ≥ high school	327	68.1	66	20.2				
Paternal education < high school	115	24.0	31	27.0	1.38	0.85-2.23	0.189	
Paternal education ≥ high school	365	76.0	77	21.1				
Multiple children	263	54.8	68	25.9	1.54	0.99-2.39	0.053	
Single child	217	45.2	40	18.4				
Multivariate logistic regression analyzes			•					
Age ≤ 6 months					2.24	1.25-3.72	0.002	
Multiple children					1.48	0.94-2.35	0.088	
Maternal education < high school					1.38	0.87-2.20	0.166	

^{*}GMCD: Guide for Monitoring Child Development.

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environment. The full completion rate of the Expanded GMCD was high and similar across sexes, parental education levels and numbers of children in the family but families of the youngest children were less likely to fully complete the Expanded GMCD. This research conducted in Turkey, provides evidence for its potential applicability in other settings. The Expanded GMCD offers a practical tool incorporating ICF and Nurturing Care frameworks for all children regardless of their health or developmental condition. Bridging contemporary theories and frameworks of child health and development, the Expanded GMCD, may help fill the gap in the literature on tools that are urgently needed to obtain comprehensive information on children and families.

Tools for social history taking do exist and their use has been shown to improve recognition of the unmet social needs of children and families [22]. Most of these tools, however, are separate screening checklists on certain aspects of social history such as poverty [22] or maternal mental health [23]. Significant barriers to using multiple separate screening tools in clinical care include a lack of time, resources, training and education, awareness of community resources and case management capacity [24]. Our findings indicate that the Expanded GMCD may offer the advantage of using one comprehensive tool covering all components of child health and development. In this study nearly 80% of families fully completed the Expanded GMCD and nearly 90% fully completed at least three of four domains. The rate of completion was higher for families of children aged older than 6 months. We postulate that this high rate of completion of a comprehensive tool such as the Expanded GMCD, if found to be true in other settings, would revolutionize pediatric history taking, particularly for low-resource settings such as low and middle-income countries. Families of the youngest children were less likely to fully complete the domains of the Expanded GMCD related to functioning, activities and participation. An explanation of this finding is supported by research which has shown that families of young infants are less knowledgeable about early childhood development [25]. This finding points to the need for employing explanatory or educational approaches to elicit responses to the Expanded GMCD questions for parents of young infants.

The largely open-ended question structure of the Expanded GMCD differs from tools utilizing only "yes/no" checklists [22]. Performance on open-ended questions has been found to correlate with quality of self-explanations, whereas performance on multiple-choice questions correlates with prior knowledge on topic [26]. In contexts where caregiver knowledge of child health and development may be low, the written open-ended question technique may have advantages for obtaining information. The fact that globally we are leaving paper and pencil behind and using digitalized tools may be a barrier to the applicability of the Expanded GMCD. Recent research found that fifth grade adolescents' responses to open-ended self-reflective questions were longer and with richer content on computerized than on paper surveys [27] indicating that the next generation of parents will have better digital writing and responding skills than with paper and pencil. In an era when a growing number of parents are using written communication, digitalized versions of tools such as the Expanded GMCD may offer rich information on child development and may promise alternatives to using digitalized checklist which would provide limited information.

The main strength of this study is the design which avoids the Hawthorne effect [28]. To avoid the effect of participating in research that modifies individual's behavior, and to ascertain real life applicability, families completed the Expanded GMCD as a routine procedure. The large sample size and low refusal rates are further strengths. The urban, single center setting where the Expanded GMCD originated is important limitation of the study. The longstanding experience, dedication and diligence in using the tool by the clinicians in this center may have increased its completion rates by families. The Expanded GMCD is for children of all ages and families of all socio-demographic characteristics. This study, however, included children in their early years and the sample was skewed towards educated parents. Further research, therefore, is needed to investigate the applicability of the Expanded GMCD in multiple, preferably international settings, including older children, and families with lower education levels.

As this manuscript was being prepared during the coronavirus disease pandemic, the Expanded GMCD was used at Ankara University Developmental Pediatrics Division to obtain information through electronic mails and telephone contact and was the crucial component of providing remote care and telemedicine to children and families. Using the Expanded GMCD, our team of clinicians was able to rapidly re-read the comprehensive information on their patients that required follow-up, to hold telemedicine sessions with them having holistic information about the child and the family, and were able to rapidly obtain such information from newly referred families. These anecdotal findings on the usefulness during pandemic may support the efforts of child health providers that are struggling to obtain comprehensive information on their patients and their families at a distance.

Conclusion

Tools that provide comprehensive information about children and families can be applied in real-life settings are of critical importance. The results of this study indicate that the Expanded GMCD, a written semi-structured tool can be applied to decrease the face-to-face time required for detailed history taking. Bridging bio ecological theory, family-centered care, ICF and NCF, the Expanded GMCD may serve to address the paucity of comprehensive assessment tools that can be used for children and families.

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