IMPACT OF TRAINING HEALTH EXTENSION WORKERS IN RELATION TO CHILD MENTAL HEALTH CARE IN RURAL ETHIOPIA

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A DISSERTATION FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN EPIDEMIOLOGY OF MENTAL HEALTH, ADDIS ABABA UNIVERSITY, ETHIOPIA

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Impact of training health extension workers in relation to child mental health care in rural Ethiopia

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External Examiner	Date
Internal Examiner	Date
Internal Examiner	Date

Dedication

This dissertation is dedicated to children with mental health disorders including autism, who lost their lives because of problems related to mental health illness.

LIST OF ORIGINAL PAPERS

This thesis is based mainly on the following papers, which are referred to in the text by their Roman numerals**:**

I. Tilahun D, Hanlon C, Fekadu A, Tekola B, Baheretibeb Y, Hoekstra RA. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Services Research* 2016; 16:152. DOI 10.1186/s12913-016-1383-9

II. Tilahun D, Hanlon C, Araya M, Davey B, Hoekstra RA, Fekadu A. Training needs and perspective of health extension workers in relation to integrating child mental health care in to primary health care service in a rural setting of sub-Saharan Africa. *International Journal of Mental Health System* (2017) 11:15 DOI 10.1186/s13033-017-0121-y

III. Tilahun D, Fekadu A, Tekola B, Araya M, Roth I, Davey B, Hanlon C, Hoekstra RA. Ethiopian community health workers' beliefs and attitudes towards children with autism: impact of a brief training intervention. *Autism (Mansucript under review).*

Acronyms and Abbreviations

AAU	Addis Ababa University
ASD	Autism Spectrum Disorder
AMREF	African Medical and Research Foundation
CHEWs	Community Health Extension Workers
CHW	Community Health Worker
DD	Developmental Disorder
DHS	Demographic and Health Survey
DALY	Disability Adjusted Life Years
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – 4th edition
FMoHE	Federal Ministries of Health and Education
GBD	Global Burden of Disease
HEAT	Health Education And Training
HEAT+	Enhanced Health Education And Training
HEWs	Health Extension Workers
ICD-10	International Classification of Diseases, version 10
ID	Intellectual Disability
LMIC	Low- and Middle-Income Countries
MDGs	Millennium Development Goals
MoH	Ministry of Health
NGO	Non-Governmental Organization
OU	Open University
PI	Principal Investigator
PHC	Primary Health Care
PHCWs	Primary Health Care Workers
SPSS	Statistical Package for the Social Sciences
UNDP	United Nations Development Programme
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
WHO	World Health Organization

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Abstract

Back ground: Child mental disorders, including autism, are major contributors to the global burden of disease leading to long lasting burden, disability and cost toward affected children and their families. These problems are aggravated by severe shortage of services. Access to services is further impeded by negative beliefs and stigmatising attitudes towards affected children and their families. Task-shifted care provided by community health extension workers (HEWs) has the potential of increasing access to services, and improving community perceptions. This study was conducted as an initial step for developing interventions to improve task-shifted care provision for children with autism and their families.

Objective: This thesis is based on three sub-studies that aimed to evaluate: (i) experiences of stigma, explanatory models and unmet needs of caregivers of children with autism (sub-study 1); (ii) the training needs of HEWs to provide integrated child mental health care (sub-study 2); and (iii) the impact of training HEWs through the Health Education and Training (HEAT) programme in relation to child mental health disorder including autism, and appropriateness to the needs of HEWs and affected families in Ethiopia (sub-study 3).

Methods:

Study setting: The first sub-study was conducted in Addis Ababa, while the second and third sub-studies were conducted in the Southern region.

Study design: The studies were primarily cross-sectional with a mixed-methods approach in sub-study 2.

Participants and methods

Sub-study 1: Participants were caregivers (n=102) of children with developmental disorders—two third of whom were caring for children with intellectual disability (n=68) and a third for children with autism (n=34). Caregivers' perceived experiences of stigma (Family Interview schedule) and explanatory models of illness and unmet needs were assessed. Data were subject to descriptive and multi variate analysis.

Sub-study 2: In a mixed study approach, 104 HEWs who had received HEAT training were interviewed using a structured questionnaire designed to assess their experience and service practice, and 11 HEWs were involved in in-depth interviews. The quantitative data were subject to descriptive analysis while the qualitative (in-depth) interviews were subject to framework analysis.

Sub-study 3: participants comprised of three groups of HEWs: i) HEWs who completed a basic mental health training module (HEAT group, N=104); ii) HEWs who received enhanced training, comprising basic HEAT as well as video-based training on developmental disorders and a mental health pocket guide (HEAT+ group, N=97); iii) HEWs untrained in mental health (N=108). All participants completed a questionnaire assessing beliefs and social distance towards children with autism. Impact of training was assessed by comparing attitudes, experiences and service practices between the three groups.

Results:

***Sub-study 1*:** Most caregivers reported experience of stigma: 43.1% worried about being treated differently, 45.1% felt ashamed about their child's condition and 26.7% made an effort to keep their child's condition secret. Reported stigma was significantly higher in caregivers who had sought traditional help ($p<0.01$), provided supernatural explanations for their child's condition ($p=0.02$) and in caregivers of Orthodox Christian faith ($p=0.03$). Caregivers gave a mixture of biomedical and supernatural explanations for their child's condition. The biggest reported unmet need was educational provision for their child (74.5%), followed by treatment by a health professional (47.1%). Most caregivers reported that talking to health professionals (86.3%) and family (85.3%) helped them to cope.

Sub-study 2: Most HEWs (88.5%; n=93/104) reported that they were interested in the training provided and all respondents considered child mental health to be important. Participants in the qualitative interviews considered the problem of child mental disorders to be widespread and to cause a large burden to the family and the affected children. They reported that improving their competence was important to address the problem and to tackle stigma and discrimination. Participants also listed some barriers (e.g. lack of competence, stigma and institutional constraints), and opportunities (e.g. staff commitment, and positive attitude) toward service provision.

Sub-study 3: Training intervention had significant positive impact on belief, attitude and social distancing. HEAT+ trained ($Z=-6.24$, $p< 0.001$, $r=-0.44$) and basic HEAT trained ($Z=-6.14$, $p< 0.001$, $r=-0.42$) HEWs were more likely to believe that children with autism can improve their language skills compared to untrained HEWs. Both the HEAT ($p=0.004$) and HEAT+ group ($p<0.001$) showed fewer negative-beliefs towards children with autism than the untrained-group. The HEAT+ group in turn displayed fewer negative-beliefs than the HEAT-group ($p<0.001$).

Both the HEAT ($p<0.001$) and the HEAT+ group ($p<0.001$) showed decreased social-distance towards children with autism compared to the untrained-group; the HEAT+ group displayed a lower preferred social-distance than the HEAT-group ($p=0.017$). Planned contrasts using Bonferroni correction for multiple comparisons revealed that the HEAT+ group had significantly lower positive-beliefs scores than the untrained-group ($p=0.01$).

Conclusions: Caregivers of children with developmental disorders and autism have high levels of unmet needs and perceived stigma. HEWs have high levels of motivation to engage in integrated child mental health care and are important resources in scaling up care for child mental health. Brief training has the potential to equip HEWs for the task of supporting integrated child mental healthcare. These findings have relevance for task-sharing and scale-up of autism services in low-resource settings worldwide.

Recommendation: It appears that caregivers and children with developmental disorders and autism are neglected. Appropriate policy response should include strategies to guide healthcare delivery to children with mental health problems including autism. The tools used in this study may support such a policy response.

Keywords: Stigma, *Child community health care**,** Impact of training; Autism; child mental disorder, child developmental disorder, health extension workers; Ethiopia*

1. Introduction

1. 1 Background

Children's mental health refers to the the capacity of children to accomplish and maintain optimal psychological functioning and wellbeing. Promotion of mental health of children is essential whether or not they are suffering from mental health problems (1). However, many children suffer from mental disorders including developmental disorders (DD). DD is umbrella term covering disorders such as autism spectrum disorder (ASD) and intellectual disability (ID). A mental illness or disorder is diagnosed when a pattern of signs and symptoms is identified that is associated with impairment of psychological and social functioning (1). The overall prevalence of mental disorders among children is about 20% (2) and has ranged from 12% to 29% among children visiting primary care facilities (3-5). Many mental disorders usually have a childhood onset (5, 6) and tend to persist into adulthood. Developmental disorders begin in childhood and persist into adult life, with increased vulnerability to many communicable and non-communicable diseases as well as other mental disorders requiring additional attention by health-care providers (7).

Autism and developmental disorders are becoming major contributors to the global burden of disease (GBD) with major disability and costs for affected individuals, their families and the community (5, 6). These burdens on children may include physical illness, violence toward other children and disturbance of peers from learning, as well as increased likelihood of unemployment (8, 9). The burden on families ranges from economic difficulties to emotional reactions to the illness, the stress of coping with disturbed behaviour, the disruption of household routine and the restriction of social activities (9-11). The other challenges on parents are an increasing personal stress, impinging on interpersonal relationships, as well as increasing isolation experienced by parents at a personal and social level across various contexts (12).

The large burden of autism and other mental disorders in children is made worse by stigma and discrimination surrounding general population and health care workers (13, 14). Stigma is an actual or inferred attribute that damages the bearer's reputation and degrades him/her to a socially discredited status (15, 16) and may be experienced or felt and/or enacted by others (16). While all people with mental disorders suffer discrimination, children are the least capable of

advocating for themselves and less likely to temper a negative remark with other more positive feedback, and may therefore more easily accept negative, misapplied labels. The negative and misapplied labels include: bias, stereotyping, fear, embarrassment, anger and rejection or avoidance; violations of basic human rights and freedoms; denial of opportunities for education and training; and denial of civil, political, economic, social and cultural rights (13, 15-18). Additionally, stigma takes special forms for childhood mental disorders; notably parents or family members may experience secondary stigma by affiliation with the affected individual and/or be the target of enacted stigma (13, 16, 17), that is to say stigma often results in parents being blamed for the mental health problems of their children; it is an important burden to parents and community (18-21). The worst consequences of the stigma of mental illness are when the patients, family members, and care-givers surrender to the public stigma and stigmatize themselves (self-stigma) (22).

However, inspite of their relevance as one of the main cause of health-related disability and long lasting effects throughout life, the mental health needs among this age group are neglected, especially in low-income and middle-income countries (5, 6, 23). Moreover severe shortage of health care professionals creates significant challenges and this problem are exacerbated by their mal-distribution that left those most in need (the poor and marginalized groups as well as those living in rural areas) (24). Most low-income African countries, including Ethiopia, have a severe shortage in mental health care provision including for autism, resulting in high treatment gaps (23). Currently there are only few psychiatrists working in Ethiopia, of whom only two are specialized child psychiatrists. Moreover, specialized child mental health clinics are limited to Ethiopia's capital Addis Ababa and are therefore unavailable to the majority (85%) of families who live in the rural areas of Ethiopia.

To overcome all this challenges and unmet needs of training among Primary Health Care Workers (PHCWs) including Community Health Workers (CHEWs) and caregivers, for Low and Middle Income Countries (LMICs), where resources are severely limited, the World Health Organization (WHO) has proposed the development of community mental health services through integration of mental health into the existing primary health care system and mobilization of community resources (24, 25). Community health workers are a particularly valuable resource in this regard and have the potential to play a vital role in improving

community awareness, preventing stigma, directing children with disorders to services providing appropriate care and working with families and communities to support affected children to fulfill their potential needs.

Ethiopia also launched a community-based health services extension programme in 2003 to address and improve the general health care facilities for people living in rural areas. Since then more than 38,000 rural health extension workers (HEWs) have completed a one year training course before starting work in rural health posts of Ethiopia (26). However, HEWs lack the skills required to make an appropriate diagnosis, advice/counsel, awareness raising, and provide a reasonable standard of care when people present with mental problems. Effective training programs are required to develop the mental health skills of HEWs and generalist PHC staff (7, 27).

Child mental health in Ethiopia

Mental Health services in Ethiopia are primarily centralized around Amanuel Mental Specialized Hospital, in the capital city. Child psychiatry services are not available in Ethiopia, and children are referred to Yekatit 12 Hospital (general hospital) or St Paul Hospital (general hospital) with psychiatric wing) from all of the country. However, the Federal Ministry of Health of Ethiopia has recently issued the National Mental Health Strategy 2012/13 – 2015/16 (28). The strategy acknowledges the importance of decentralization of mental health services. Although Ethiopia has recently developed a national mental health strategy as, there is no mental health policy and no specific programs including child mental health including childhood autism. Additionally, in many countries including Ethiopia, child mental health services are regarded as a subset of general mental health services or child health services, or as a minor extension of these services (5, 29). Most of attention for example interms of funding for mental health services is devoted to adult services, which makes it difficult to develop appropriate child mental health services(5, 6, 29). If child mental health services were to be viewed as a distinct category of health care with unique requirements, specific funding arrangements and policy development would be facilitated. Thus, this study may help the policy makers and other concerned body as an output and may narrow the gaps in this area.

1.2. Statement of the problem

Mental disorders in children that include childhood developmental disorders including autism, and behavioural disorders impact seriously the behavior of children and their capacity to learn (1, 2). They are common and wide spread; about 20% of children have mental health disorders in both developed and developing countries (6, 10). In Ethiopia, childhood mental disorders are among the leading mental health burden of the health sector with prevalence rates of 12-25% (10, 30). Despite their relevance as one of the main cause of health-related disability and long lasting effects throughout life, the mental health needs among this age group are neglected, especially in low-income and middle-income countries (LMIC) (5, 6, 23). It has a large impact not only on the individual but also on the caregivers and contributes to health problems, social and economic burdens and poor quality of life on the individuals, their families and productivity of societies (12, 25, 31). Moreover severe shortage of health care professionals creates significant challenges and mal-distribution of service delivery for those most in need, particularly in rural areas, and places specialist psychiatric care out of the reach of most people and creating severe difficulties in the delivery of appropriate mental health care (7). Most LMIC have a severe shortage in mental health care provision including autism, resulting in high treatment gaps (5, 23).

In Ethiopia there is also limited health care facility with over 90 million people. Currently there are only few psychiatrists working in Ethiopia, of whom only two are specialized child psychiatrists. There are no clinical psychologists and only few non-clinically trained psychologists work on inpatient wards, but none of them specialize in child mental health. Moreover, specialized child mental health clinics are limited to Ethiopia's capital Addis Ababa and are therefore unavailable to the majority (85%) of families who live in the rural areas.

The identification of, treatment and suitable care for, children with mental health disorders including autism is further impeded by stigma surrounding general mental health disorders or autism and misconceptions of the causes of mental health disorders or autism. Like the general public, primary health workers often hold the stereotypical views that people with mental illness are unlikely recover and people with severe mental illness are dangerous and violent (32, 33). Studies in Nigeria (32) and Ethiopia (34) indicate that stigmatization of mental illness is widespread in sub-Saharan African communities. Mental health problems or child DD including

autism are frequently attributed in to supernatural forces or to a curse in these communities as well as in tertiary health workers (27, 32, 34). Autism is often co-morbid with epilepsy; the belief that epilepsy is contagious is widespread in Ethiopia (34) and it is commonly believed that epilepsy is caused by the person being possessed by the devil. People with religious or supernatural beliefs of causation may have less tolerant attitudes towards people with mental health problems (34); children with autism and their families are more likely to be stigmatised because of these misconceptions, these views and beliefs may therefore impede both identification and successful community rehabilitation of people with mental health problems and of children with autism, with or without co-morbid epilepsy.

To solve this problem since the Alma-Ata declaration on primary health care in 1978 community health worker cadres have been occurring in many countries across the globe (24). In addition, the integration of mental health into PHC as the optimal strategy for addressing the global burden of disease has been advocated by the World Health Organization (WHO) and other studies (5, 35-37). Similarly to address basic health provision and improve the general health care provision for people living in rural areas, Ethiopia launched a community-based health services extension programme in 2003. Since then more than 38,000 health extension workers (HEWs) have completed a one year training course before starting work in rural health posts of Ethiopia. Almost all of these HEWs are women; every rural kebele (the smallest administrative unit in Ethiopia, comprising about 5000 people) is assigned two HEWs. The HEWs deliver primary community healthcare services and are engaged in promoting health and raising health awareness. In addition to providing services at their health post, HEWs are actively engaged in outreach services by visiting the houses of people in their community and training model families and community volunteers (38).

Study on evaluation of the first intake of health extension program (HEP) indicated some remarkable successes, including a significantly higher proportion of children vaccinated against communicable diseases and an increase in the use of bed nets to prevent malaria (39). However, there was little effect of the programme in the context of child mental disorder including autism, since the initial programme did not include any mental health training including autism. In addition, different studies depict quality and appropriateness of initial training to rural HEWs

was inconsistent and unsatisfactory (40, 41). Large gaps in competencies for knowledge, skill, ability, attitude, confidence and motivation and willingness also detected (40, 41). To address these concerns, the Ethiopian government initiates their Health Education and Training (HEAT) programme in Ethiopia to develop a comprehensive curriculum of government-approved modules to upgrade the HEWs.

The HEAT programme curriculum covers key topics in child and maternal health, family planning and sexual health, environmental hygiene, communicable and non-communicable diseases. Ten study sessions specifically concern mental health, including a focus on mental health management and assessment, mental illness prevention strategies and childhood developmental and behavioural problems including autism. However, lacked details on childhood developmental disorders and virtually no content on autism. The first cohort of about 1300 HEWs were trained using the HEAT modules in a pilot project across the country at the launch of HEAT in 2012; since then, over 12,700 have completed the upgrading training using HEAT study materials (Personal Communication, Federal Ministry of Health, 2016). Following their HEAT training, we examined the experiences and remaining training needs of HEWs who had just completed the HEAT pilot. In response to these findings, we developed an enhanced version of the HEAT mental health training, called HEAT+, specifically targeting autism and intellectual disability in children. In the HEAT+ research project we surveyed the experience, knowledge and attitudes of HEWs who were trained using HEAT or HEAT+, and compared their experience, knowledge and skills with HEWs not yet trained in mental health or developmental disorders. The current research project aimed to provide an evaluation of the impact of the basic and enhanced HEAT mental health module training materials in relation to child mental health care, including autism, and to support further development of this part of the curriculum to ensure maximum impact on families affected by these conditions.

1.3. Rationale and significance of the study

In communities where child mental health disorders are highly stigmatized, programmatic support and partnerships between health providers and families is required. To achieve sustainable reductions in child mental health disorder including autism, national policies and programs must be complemented by effective community-based actions. These actions must address and minimize local causes of child mental health disorders, improve access to effective

care and provide ongoing support for rehabilitation. A key dimension of this strategy is enabling health extension workers, families and societies to maximize their knowledge, positive beliefs and attitudes, and reduce unhelpful belief, negative stereotype and social distance towards child mental health disorders including autism, to minimize stigma within the community and the health profession, at the same time as increasing the availability of mental health care. This process requires effective mobilization of communities and shifting from a centralized to a more decentralized approach, with wider participation on the part of the community. Partly due to the complexity of the causes of child mental health disorders including autism, the efforts made to date have been minimal and to no avail.

A new opportunity is now present to improve the care of children with mental health disorders including autism. Children and adolescents are identified as a vulnerable group deserving special attention within the recently launched national mental health strategy of Ethiopia. Furthermore, the ministry of health has included training in mental health care in the upgrading of HEWs across the country.

This PhD thesis describes a timely research study which provides the opportunity to optimise the impact of the MoH initiatives. The current study provides a baseline measurement of the current knowledge, attitudes and practice of child mental health disorders in general and autism in particular, among HEWs in Ethiopia. The existing MoH HEAT mental health study materials were then enhanced based on feedback provided by the initial cohort of HEWs students in the pilot, and by parents of children with mental health disorders including autism. The enhanced mental health study material was implemented, so that it benefitted the second cohort of upgrading HEWs and future cadres of health workers can benefit from it. The effectiveness of the enhanced HEAT mental health module to increase awareness on child developmental disorders including autism and stigma (belief, attitude and social distance) was evaluated in a follow-up measurement.

Finally, the findings of this study have been and/or will be disseminated through peer-reviewed publications and international conferences. The enhanced mental health module is made openly available online in a format suitable for print to maximise future impact.

1.4. Literature review

In order to conceptualize the study, the theoretical bases were reviewed from the existing related literatures and a conceptual framework was developed. The literature review tried to address the stigma, explanatory model and unmet needs of caregivers with child with autism/ID, training needs and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care in to primary health care service and the impact of training program on community health workers in relation to child mental health care including autism. This reviewed literature used for further development of the curriculum and training materials for community HEWs and then to overcome severe shortage of child mental health care provision, treatment gap and unmet need of caregivers of child with developmental disorders. International, national and local literatures were reviewed with special emphasis to the developing countries.

1.4.1. Sigma, explanatory model and unmet need of caregivers of children with developmental disorders

Epidemiological studies in low- and middle-income countries of the prevalence of child mental health problems, including developmental disorders, indicate that these conditions are at least as prevalent as in high-income countries (7). In a meta-analysis, the prevalence of intellectual disability (ID) was higher in low-income countries (1.6%) than in high-income countries (1.0%) (42). The global prevalence of autism spectrum disorder (ASD) is estimated to be around 0.6%, but there are no prevalence data available from anywhere in Africa (43). ASD and ID are lifelong developmental disorders that have a large impact not only on the individual but also on the caregivers (12). The challenges experienced by caregivers of children with ASD or ID have been relatively well documented in high-income countries (15, 16, 18, 19), but less is known about the experiences of caregivers from low- and middle-income countries (20, 21, 44, 45). Studies from high-income (15, 16, 18, 19) and low- and middle-income countries (11, 44) have shown that families with children with autism or ID frequently experience stigma. Both felt stigma (referring to feelings of shame and the anticipation of prejudice that prevents people from talking about their experiences and impedes them looking for help) and enacted stigma (external stigma, such as evasion and discrimination) are common (46). In India, caregivers indicated that they would be ashamed if people knew someone in their family had been diagnosed with autism (44). In Tanzania, caregivers of children with mental illness, including ID and ASD, reported that they experienced social exclusion and discrimination (20). Another challenge identified in

previous studies is that caregivers may hold misconceptions about the perceived causes and prognosis of developmental disorder in their children (47). Severe mental disorders (14) and autism (32) are frequently attributed to supernatural or traditional forces in sub-Saharan Africa (14) and in Asia (47); these forces may include lineage curses, enemies, an action of the devil, or a punishment from God (14, 32).

Studies in high-income countries (19, 47, 48), India (44) and among Indian parents living abroad (49) have found that caregivers of a child with a developmental disorder tend to utilise a wide variety of treatment strategies, including biomedical as well as traditional or alternative and complementary treatments. Many caregivers also report financial difficulties, either directly, due to the costs of the treatment sought (20, 47) or indirectly, because of caregivers foregoing opportunities to engage in income generating activities (20). In studies from high-income (19, 47) and low- and middle-income countries (20, 44, 50) caregivers have been reported to respond actively to the challenges they faced through a range of approaches: talking to a health professional, family members or religious leaders, praying and employing spiritual practices and accessing instrumental social support.

Although these previous studies have provided important insights, the challenges experienced by caregivers of children with ASD and ID have not been fully understood or described in different socio-cultural contexts. Studies in sub-Saharan Africa focusing on developmental disorders are especially rare. A study from Nigeria investigated healthcare worker perspectives on autism (32) and a qualitative study from Kenya explored the perceptions of both professionals and parents (51). Three further studies from Africa have explored parental views (20, 52) or views from a general population sample (14) in relation to general mental health problems rather than developmental disorders specifically. Moreover, many of the previous studies in low- and middle-income countries were purely qualitative and were thus unable to compare groups statistically (20, 44, 46).

In Ethiopia, as in many other low-income countries, there are limited services for children with developmental disorders and their caregivers (45). Out of a population of over 90 million people, nearly half of whom are children, there are only two trained child psychiatrists and the available specialised child mental health clinics are limited to the capital city, Addis Ababa. In planning

future intervention programmes for children with developmental disorders it is essential to better understand the perspective of the caregivers, particularly in terms of examining the experiences and challenges of caring for children with ASD and/or ID among caregivers, particularly in terms of examining stigma experienced by families, understanding the perceived causes of the illness, mapping out the interventions tried and coping strategies practiced as well as determining the unmet needs of caregivers. A good understanding of these factors is essential for designing and implementing future interventions for Ethiopia and other low resource settings to improve the lives of children with developmental disorders and their families.

1.4.2. Training of Health extension workers

Since the Alma-Ata declaration on primary health care in 1978, community health worker cadres have been occurring in many countries across the globe (24). Studies show there are severe shortages of service provision for children with developmental disorder including autism especially in LMIC (53, 54). However, nowadays there have been few studies that show potential roles and training needs of community health workers within primary health care and have received great acknowledgement due to the increasing critical shortage of human resources and unequal distribution within health services (55-57). Similar to other developing countries, Ethiopia has also very limited health care provision (58). To address the health needs of the population, the government of Ethiopia has launched a comprehensive Health Sector Development Plans (HSDP) in 2003/04 (59, 60). As part of the HSDP, the government has introduced an innovative health program called Health Extension Program (HEP) in 2002/03 (61). The philosophy of HEP is that if the right knowledge and skill is transferred to households, they can take responsibility for producing and maintaining their own health, with the aim of accelerating primary health care coverage and ensuring access to basic health services to the underserved rural population, the country launched a new community-based initiative called the Health Extension Program (HEP) in the year 2003 (38). HEP is composed of four main themes: Disease prevention and control, family health, hygiene and environmental sanitation and health education and communication. These four themes consist of about sixteen health packages which mainly deal with promotive and preventive health services (61). The program is implemented by new health carders called Health Extension Workers (HEWs) who were trained solely for the implementation of the program. Basically, all HEWs are women who completed grade ten and received technical and vocational training for one-year (61). By the end of 2010, a total of

38,000 HEWs were trained and deployed in each rural village throughout Ethiopia to serve the community (60). Two HEWs were assigned to each kebele throughout the country. Kebele is the smallest administrative unit in Ethiopia. Each kebele has a Health Post (HP) which serves as the operational center for two HEWs. These new cadres were selected from the communities in which they reside in order to ensure acceptance by community members. They are the first point of contact of the community within the health care delivery system (38). The training curriculum was designed based on 70% practical and 30% of theoretical sessions (61). The main task of HEWs is increasing the awareness/knowledge and skill of the community members and households to deal with diseases and be able to access to health services. HEWs are required to spend 75% of their time conducting house –to- house activities to teach and help households and community members to adopt healthy behaviors (38).

1.4.3. Training needs and perspectives of HEWs in integrating child mental health care

Globally, 10 to 20% of children are estimated to have mental health problems (6, 10). In Ethiopia, childhood mental problems have been found to affect 12-25% of children (62-64) and to be associated with disability, cost and poorer quality of life of children and their families (6, 10, 31, 65, 66). Moreover, the treatment gap approaches 90% in low and middle income countries (LMIC), mainly due to severe shortage of trained manpower (5, 67).

Community health extension workers (HEWs) may play a major role in addressing the treatment gap in LMIC (57, 65, 68). There is clear evidence of the beneficial role of community health workers in promoting immunization uptake, improving outcomes for acute respiratory infections and malaria care in LMIC (69-72). There is also evidence that identification and treatment of mental disorders may be improved through training of HEWs (5, 73-75). Delivery of integrated care at the Primary Health Care (PHC) level supported by HEWs may even reduce stigma and discrimination (73, 75-77). However, at present there is insufficient evidence to justify recommendations for the deployment of CHWs for child mental health care.

In Ethiopia, the Health Extension Program was launched in 2003 (59). Since that time, around 38,000 HEWs have been deployed to rural areas across the country. HEWs are mostly female health workers tasked mainly with providing promotive, preventive and rehabilitative care after one year of training. More specifically, HEWs in Ethiopia promote immunization uptake,

antenatal care and prevention of malaria, both at their health post and through outreach services by visiting the houses of people in their community (78, 79). Evaluation of the Health Extension Programme in Ethiopia has indicated some notable successes, including a higher proportion of children vaccinated against communicable diseases and an increase in the use of bed nets to prevent malaria (39). However, HEWs have not been involved in the care of children with developmental disorders in Ethiopia. Additionally, the initial HEW training programme did not include any training in mental health. To address these concerns, in 2011 the Federal Ministry of Health (FMOH) of Ethiopia, in partnership with the Open University UK, developed a new training programme to upgrade HEWs (to level 4 or diploma grade), which included training in mental health through the Health Education and Training (HEAT) programme. When this study was initiated about 1,300 HEWs have been trained in the HEAT modules in a pilot project across the country and currently 12,700 have completed the HEAT training and have been upgraded to Level-4 (Federal Ministry of Health). However, competency needs and perspectives of HEWs about the integration of child mental health care into their routine practice have not previously been explored. Therefore examining training needs and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care into community-based PHC services in Ethiopia is very important as they are the fundamental unit for designing, development and enhancement of training materials for child mental health care and for most of the HEP packages and means to overcome treatment gap problem among children with mental problems and childhood autism.

1.4.4. Impact of training community health workers related to autism

Autism and other developmental disorders (DD) are increasingly recognised as conditions associated with long-term burden, disability and cost requiring global action (5, 6, 10). The global prevalence of autism is estimated to be around 0.6% (43). The prevalence of autism in sub-Sahara Africa is unknown (43), but prevalence studies of general mental health problems and intellectual disability in low and middle income countries (LMIC) suggest that such problems are at least as prevalent as in high-income countries (7, 80). In most LMIC mental health and developmental problems are aggravated by a severe shortage in mental health care provision, resulting in large treatment gaps (23).

Ethiopia is a country located in the horn of Africa with a population of almost 100 million people, half of whom are children. Our recent situational analysis of autism services in Ethiopia (81) showed that diagnostic and educational services for children with autism are largely confined to Ethiopia's capital Addis Ababa and therefore unavailable to the majority (85%) of families who live rurally. There are only two child psychiatrists working in Ethiopia; the two schools for children with autism in Addis Ababa are both highly oversubscribed with long waiting lists. The identification, care and treatment of children with autism are further hindered by stigma, negative stereotypes and misconceptions about the causes of developmental disability and child mental illness (52, 82). Supernatural explanatory models, for example, attributing the child's problems to a curse or spirit possession are common, both in caregivers of children with DD (82) and in parents of typically developing children (52). Ethiopian caregivers of children with a developmental disorder report high levels of stigma; higher experienced stigma was associated with seeking help from traditional institutions and providing a supernatural explanation for their child's condition (82). Supernatural explanatory models of mental illness and negative attitudes towards people mental health problems are also common among nursing staff in Ethiopia (83, 84). Examining beliefs regarding autism among health professionals, studies in Kenya (51) and Nigeria (32) indicate that similar negative beliefs and misconceptions about the causes of autism are common in other sub-Saharan Africa countries. People with religious or supernatural beliefs about causation are likely to have less tolerant attitudes towards people with mental health or developmental problems (33). These views and beliefs may, therefore, hamper identification and successful community rehabilitation of children with autism. Consequently it is likely that the adult community also includes many individuals whose autism goes without recognition or support.

One of the most promising strategies to address the treatment gap for children with autism and other developmental and mental health disorders is decentralisation of mental health care provision, through task-shifted or task-shared care by non-specialists (5, 27). Community health workers, referred to as health extension workers (HEWs) in the Ethiopian health system, have a great potential to be involved in decentralised care provision.

To improve the general health care facilities for people living in rural areas, Ethiopia launched a community-based health services extension programme in 2003. Since then 38,000 HEWs completed a one-year training course before starting work in rural Ethiopia. Every rural *kebele* (the smallest administrative unit in Ethiopia, comprising about 5000 inhabitants, half of whom are children) is assigned two HEWs. The HEWs deliver primary community healthcare services consisting of health promotion and prevention packages at their health post. In addition, HEWs are actively engaged in outreach services by visiting the houses of people in their community and training model families and community volunteers (78). Evaluation of the initial Ethiopian health services extension programme indicated some notable successes, including a significantly higher proportion of children vaccinated against communicable diseases and an increase in the use of bed nets to prevent malaria (39). However, there was little impact of the programme in other health areas. More importantly in the context of autism, the initial programme did not include any training on mental health or developmental disorders.

To address these concerns, the Federal Ministry of Health (FMOH) of Ethiopia worked with The Open University (UK) to develop the Health Education and Training programme (HEAT) (OpenLearnworks website) to upgrade the training of existing HEWs. The HEAT curriculum covers topics in child and maternal health, family planning and sexual health, environmental hygiene, communicable and non-communicable diseases. Ten study sessions specifically concern mental health; though child mental health and developmental problems receive only limited attention, with virtually no content on autism spectrum disorders.

About 1300 HEWs were trained using the HEAT modules in a pilot project across the country at the launch of HEAT in 2012; since then, over 12,700 have completed the upgrading training using HEAT study materials (Personal Communication, Federal Ministry of Health, 2016). Following their HEAT training, we examined the experiences and remaining training needs of HEWs who had just completed the HEAT pilot (85). The majority of surveyed HEWs were satisfied with the HEAT training materials on mental health and over two third of HEWs indicated they used these study materials at least once a month in their job. However, 74% of the HEWs also indicated they would benefit from additional training on child mental health and developmental disorders. Qualitative interviews with a subsample of HEWs indicated HEWs feel

they lack knowledge and skills to adequately support children with developmental disorders in their community. In response to these findings, we developed an enhanced version of the HEAT mental health training, called HEAT+. This covered a range of adult and child mental health problems, and included training materials specifically focussing on autism and intellectual disability in children. In the HEAT+ research project we surveyed the experience, knowledge and attitudes of HEWs who were trained using HEAT or HEAT+, and compared their experience, knowledge and skills with HEWs not yet trained in mental health or developmental disorders.

1.4.5. Combined face to face training and video presentation vs. face to face methods

There is growing evidence that challenge related to unhelpful belief, negative attitude and social distance in managing mental health problem including autism can be reduced and improved through different training methods. Studies indicate that different program conducted by face to face lecture with different interactive and non interactive approaches have been shown to be effective in decreasing misconception (73, 86, 87), negative attitude (73, 86, 88-94) and social distance (89, 90, 94, 95). Moreover, different studies also compared the effect of face to face alone vs. video and have indicated that non interactive methods using video/film have a higher effect than lecture alone in decreasing negative attitude (96-101) and social distance (96, 97, 99, 102). A recent systematic review of prejudice reduction strategies suggested that media interventions are promising areas for future research (94). Indeed, a study exploring the impact of anti-stigma video-films on medical students' attitudes to serious mental illness showed promising results (94, 100). Given the power of audiovisual media to influence societal constructions of about misperception, negative attitude and social distance (100, 101), and the growing reputation of videos as a useful, enjoyable, and impactful tool in behavioural medical education (101, 103), brief videos may offer an alternative and inexpensive way of tackling misperception negative attitude and stigma in this population through raising awareness. Attempts to use educational training program using combined lecture with video method in child developmental disorder including autism related problem however are rare. Moreover, no studies have evaluated the impact of combined effect of lecture and video compared to lecture alone on health education and training program in relation to mental illness including autism.

1.4.6. Conceptual framework of the study

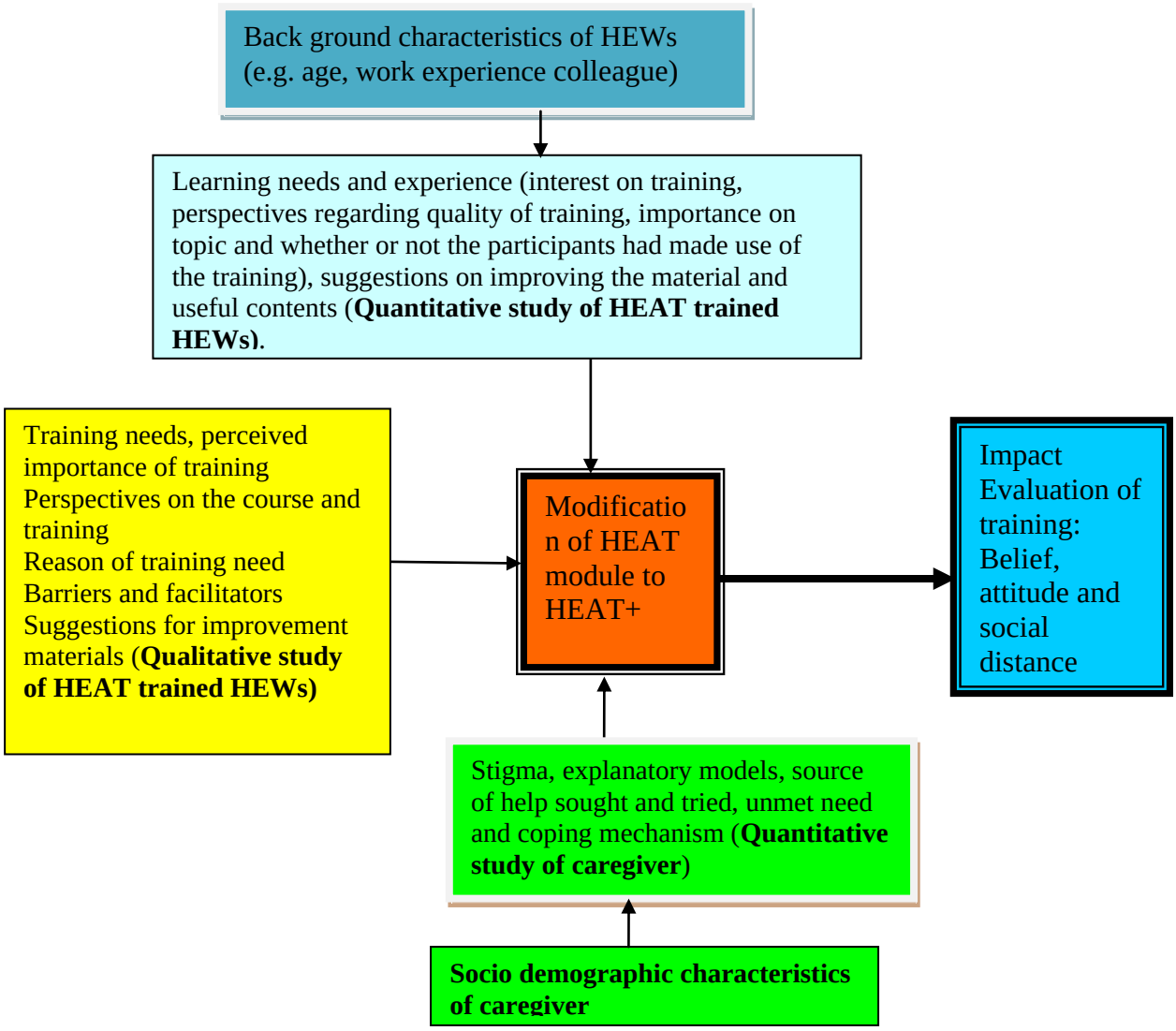


Figure 1: Conceptual framework of the study on evaluation of impact of training HEWs and appropriateness to the needs of HEWs and affected families, Ethiopia, Sept 2012 to Dec 2013.

2. Research question and objectives

2.1. Research question

1. In caregivers of children with developmental disorder, what were the stigma experiences, the explanatory models of child developmental disorder, unmet needs and coping strategies?
2. What are the learning needs and perspectives of HEWs in relation to integrating child mental health care in to primary health care services?
3. Does amendment of the HEAT training materials result in improved HEW belief, attitudes and social distance in relation to childhood autism?

2.2. Research objectives

2.2.1. General objective was:

To evaluate the impact of the mental health module of the HEAT training programme among HEWs in terms of improvement in belief, attitudes and social distance in relation to child mental health care including autism and appropriateness to the needs of HEWs and affected families.

2.2. Specific Objectives:

1. To determine the experience of stigma, explanatory models, unmet need and coping strategy in caregivers of children with child mental health problems specific to developmental disorders (autism/ID).

2. To examine training needs and perspectives of HEWs in relation to integrating child mental health care including autism in to primary health care services.

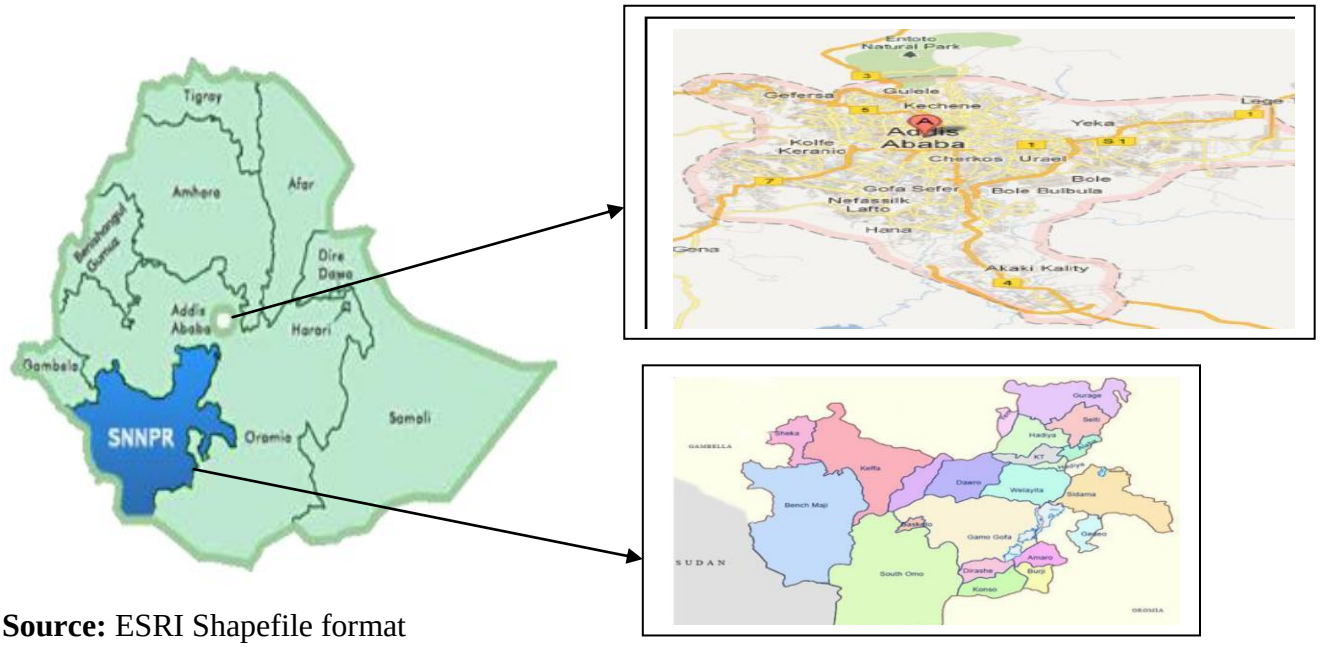
3. To evaluate the impact of training with the basic and enhanced HEAT program on belief, attitudes and social distance among HEWs in relation to childhood autism.

3. Research Methods

The study had three components or sub-studies and followed a mixed methods approach, although primarily quantitative.

3.1 Study setting

The study was located both in Addis Ababa city and in the Southern Nations, Nationalities, and People's Region (SNNPR). The study setting for sub-study 1 was located at Yekatit 12 hospital and St. Paul hospital child mental health clinic in Addis Ababa, Ethiopia. These were the only two public sector clinics in Ethiopia with specialist expertise in child developmental disorder including autism. The study setting for sub-studies 2 and 3 was located in the Southern Nations, Nationalities, and People's Region (SNNPR), one of the 11 federal administrative regions of Ethiopia. From the Ethiopian 2007 census (104) SNNPR has an estimated population of around 15 million, comprised of peoples from 45 ethnic groups. The region is predominantly rural; nearly 90% of inhabitants are residing in rural areas. The community-based health services extension programme was launched in 2003; between 2003 and 2009, 7492 rural HEWs were trained in SNNPR (105). In 2011, the first cohort of 208 HEWs from SNNPR enrolled in the HEAT training, of which 204 had completed the training successfully. In 2013 a new cohort of HEW in SNNPR were trained using the enhanced (HEAT+) mental health training materials.



Source: ESRI Shapefile format

Figure 2: Map of the study area, Addis Ababa City Administration and Southern Nations, Nationalities, and People's Region (SNNPR), Ethiopia, Sep 2012 to Dec 2013

3.2 Study design

The study employed both quantitative and qualitative methods. The design for sub-study 1 was a cross-sectional facility-based study carried out using a structured questionnaire administered in a face to-face interview to caregivers of children with ASD and/or ID. The study design employed for sub-study 2 was a mixed methods approach, consisting of a cross-sectional survey and qualitative study. The qualitative study was included to obtain a more in-depth understanding of the experiences and perspectives of HEWs. The study design employed for sub-study 3 (evaluation phase) was a cross-sectional study design, which comprised three groups: i) HEWs who completed the original HEAT mental health module; ii) HEWs who were trained using the enhanced HEAT module; iii) untrained-HEWs.

Generally, the focus this PhD study was on the evaluation of the impact of HEAT training programme among HEWs in relation to child mental health care and appropriateness to the needs of HEWs and affected families. In order to have a broad understanding on the impact of training, the initial studies of the experiences of caregivers and HEWs were conducted.

3.3. Populations

3.3.1 Source population

All caregivers of children with developmental disorders attending hospital during the study period and all HEWs who were working in rural areas of SNNPR were considered as the source population of the study.

3.3.2. Study population

The study population for sub-study 1 was all eligible caregivers of children with DD.

The study population for sub-study 2 was all eligible HEWs trained using HEAT material at two training facilities (Hawassa and Hosanna facilities) of the available four facilities for the HEAT training in SNNPR at the time of the study at base line. For the qualitative study, study population was eleven sub-sample of HEAT trained HEWs. All HEWs are female due to the policy of the Federal Ministry of Health of Ethiopia.

The study population for sub-study 3 was all eligible HEWs who completed the original HEAT mental health module in 2012 (group 1); eligible HEWs who were trained using the enhanced HEAT mental health module (HEAT+) (group 2) and all eligible practicing HEWs not yet enrolled in the upgrading programme, who had not yet received any mental health training (group 3). All HEWs are female due to the policy of the Federal Ministry of Health of Ethiopia.

3.3. Inclusion criteria and exclusion criteria

Inclusion criteria: the inclusion criteria for sub-study 1 was children aged less than 18 years, with a DSM-IV diagnosis of intellectual disability or autism, confirmed by a psychiatrist with expertise in child mental health, accompanied by caregiver. Inclusion criteria for studies 2 and 3 were rural HEWs who were working in SNNPR, Ethiopia.

Exclusion criteria: the exclusion criteria for sub-study 1 was lack of informed consent of caregivers to participate and if the child is acutely disturbed or in need of emergency medical intervention. The exclusion criteria for sub-studies 2 and 3 were lack of informed consent of HEWs to participate.

3.4 Sample size and sampling methods

Sample size for sub-study 1 was based on considerations of feasibility; all caregivers within the time period were included. The sample size for the sub-study 2 among trained HEWs was through inclusion of all HEWs trained with basic HEAT materials at the two sites (Hawasa and Hossana health facilities); and all available HEWs at the time of study were included. For the qualitative study, in-depth interviews were conducted with sub sampled HEAT-trained HEWs and participants were included in the study purposely on the basis of the administrative zone within which they worked. Sample size for sub-study 3 was calculated by power analysis (using the software PASS11-Power Analysis and Sample Size version 11) (detail sample size calculation was found on project grant #7770 to Rosa Hoekstra).

3.4.1. Sample size

Sample size for sub-study 1

The objective here was to determine the experience of stigma, explanatory models, unmet need and coping strategy in caregivers of children with child mental health problems specific to developmental disorders (autism/ID). The planned sample size was 100 consecutive attendees. Based on considerations of feasibility, all caregivers within the time period were included. Allowing for non response, 102 caregivers were recruited.

Sample size for sub-study 2

The objective here was to examine training needs and perspectives of HEWs in relation to integrating child mental health care including autism in to primary health care services. All 116

HEAT trained HEWs at the two sites (Hawasa and Hossana health facilities) were invited, 104 were available for the study and all were included. For the qualitative study, in-depth interviews were conducted with 11 sub sampled HEAT-trained HEWs included in the study.

Sample size for sub-study 3

The objective here was to evaluate the impact of training using basic and enhanced HEAT program on belief, attitudes and social distance among HEWs in relation to childhood autism. The sample size determination used power analysis. A power analysis (using the software PASS11-Power Analysis and Sample Size version 11) indicates that a sample size of 100 participants per group provides adequate power to detect modest effects of group and intervention (detail sample size calculation was found on project grant #7770 to Rosa Hoekstra). Allowing for non-response, the sample size of study comprised of: N=104, HEAT group; N=97, HEAT+ group; and N=108, untrained group i.e. a total 309 HEWs were included in the study. Specifically, (i) all HEAT-trained HEWs who studied in Hosanna and Hawassa (N=116) were invited to take part in this study; complete data were available for 104 HEWs (participation rate 89.7%). (ii) HEWs enrolled in the HEAT+ training had completed the HEAT+ mental health module on average 4 months prior, but were still completing other modules of their upgrading training and had thus not yet returned to their local community. Out of the 104 HEAT+ trained HEWs invited to take part, 97 participated (93.3%). (iii) Lastly, a total of 116 HEWs not yet trained in HEAT or HEAT+ were invited to one of the two training facilities, of which108 participated (93.1%). Thus a total 309 HEWs were included in the study.

3.4.2. Sampling methods

The sampling methods for sub-study 1 was based on consecutive caregivers' attending Yekatit 12 and St Paul's child psychiatric out-patient units in Addis Ababa, and the children they care for were diagnosed by child psychiatrists to have autism and/or intellectual disability. The caregivers were approached for recruitment into the project. Diagnoses were made by a child psychiatrist and/or psychiatrist trainees following DSM-IV criteria, after a clinical observation and an interview with the child's caregiver.

The sampling method for sub-study 2 was that first participants were identified via the regional health bureau and were informed in advance about the study. If the HEW agreed to participate in the study, the HEWs were invited to the nearest College of Health Sciences

(Hawasa and Hosana) to carry out the assessments centrally. All 116 HEAT trained HEWs were invited and 104 (89.7%) attended. All of those who attended gave informed consent to participate. For the qualitative study, in-depth interviews were conducted with 11 HEAT-trained HEWs selected purposively on the basis of the administrative zone within which they worked. This "zone-based" selection was to ensure diversity of localities of origin in order to capture the broader range of experiences.

The sampling method for sub-study 3 was that first participants were identified via the regional health bureau and were informed in advance about the study. If the HEW agreed to participate in the study, the HEWs were invited to the nearest College of Health Sciences (Hawasa and Hosana) to carry out the assessments centrally. A total of 336 HEWs were invited for the three groups i.e. (N=116, HEAT group); (N=104, HEAT+ group) and (N=116, untrained group) HEWs. The study participants in the HEAT and HEAT+ groups had all received their basic or enhanced HEAT training in the study sites Hawassa or Hosanna, two of the four available facilities for the upgrading training in SNNPR at the time of the study. The HEAT group had completed their training on average 16 months prior to the data collection and had since returned to their local community to work. All HEAT-trained HEWs who studied in Hosanna and Hawassa (N=116) were invited to return to their training facility to take part in this study; complete data were available for 104 HEWs (participation rate 89.7%). HEWs enrolled in the HEAT+ training had completed the HEAT+ mental health module on average 4 months prior, but were still completing other modules of their upgrading training and had thus not yet returned to their local community. Out of the 104 HEAT+ trained HEWs invited to take part, 97 participated (93.3%). Lastly, a total of 116 HEWs not yet trained in HEAT or HEAT+ were invited to one of the two training facilities, of which108 participated (93.1%). All participating HEWs were female. Each HEW works alongside one HEW colleague in her local community. Working alongside a colleague who had already completed mental health training may affect a HEWs' knowledge and attitudes about autism; we therefore recorded whether a HEW worked alongside a trained or untrained colleague.

3.5. **Data collection and instruments**

3.5.1. Data collection instruments

3.5.1.1. Instruments for sub-study 1

This sub-study used structured questionnaires comprising five parts: socio-demographic characteristics, family experience of stigma, explanatory model of illness, type of intervention used or desired and caregiver coping strategies. The socio-demographic section collected information on the age, marital status, religion, ethnicity, and education status of the respondents (caregivers). The family's experience of stigma in the community was measured using an adapted version of the Family Interview Schedule (FIS) (106). The original version of the FIS was developed for relatives of people with schizophrenia and was therefore adapted for use in this study to focus on caregivers of children with developmental disorders. The FIS includes 14 questions about the family's experience of stigma in the community. Each question was rated on a four-point scale where the intensity of experiencing stigma in the community was described as 'a lot' (a score of 3), 'often' (a score of 2), 'sometimes' (a score of 1), and 'not at all' (a score of 0). To assess the distribution of responses between groups, a total score was computed by summing the item scores, with a minimum score of 0 and a maximum score of 42. The internal consistency of this adapted FIS scale was good (Cronbach's Alpha = 0.92). The other sections contained questions concerning explanatory models of illness, the perceived severity and prognosis of their child's condition, interventions tried, coping strategies used and questions about service utilization. Lastly, the type of support most needed to help improve the child's condition was asked through an open-ended question: 'To help your child with slow development to improve, what would help the most?'

3.5.2.2. Instrument for sub-study 2

In the sub-study 2 both structured and open ended questions were used. The structured questionnaire comprised two parts: socio-demographic characteristics (age, religion, educational status and work experience) and learning needs and experience. The learning needs and experience questionnaire gauged the interest of participants on attending the training on child mental health and on their perspectives regarding the quality of training resources and the importance of the topic. This section also included questions on whether or not the participants had made use of the training resources in their practice, for example, whether they had organized a mental health awareness meeting in the community to discuss about mental health needs of

children. The open-ended questionnaire explored whether the study material helped in their daily practice, and solicited suggestions on improving the study material, including what the HEWs thought would be useful to include in the training. For in-depth interviews, a topic guide was prepared to guide the discussion with HEWs. The in-depth interviews expanded on the quantitative survey and probed specifically around child developmental disorders i.e. autism and intellectual disability (ID); this is because this part is included in the Mental Health Gap Action Programme (mhGAP). The in-depth interviews explored the following areas: training needs and the perceived importance of the training; perspectives on the course and training; barriers and facilitators to developing child mental health services; and suggestions for improvement of the training materials.

3.5.3.3. Instrument for sub-study 3

In this sub-study all participating HEWs were asked to complete a structured questionnaire, including a case vignette of a child with autism. Following the case vignette, the HEWs were asked various questions related to autism, including their general beliefs about autism and their preferred social distance from children with autism (a measure of what level of intimacy and interaction they would accept with a child with autism). These questions were adapted from the World Psychiatric Association programme to Reduce Stigma and discrimination Because Of Schizophrenia (107). A similar questionnaire has been used to assess attitudes towards mental illness in Nigeria (14). For this study the questionnaire is further adapted so that it focuses on autism in particular and is suited to the Ethiopian context. The adaptation was based on expert consensus.

The general beliefs questionnaire comprised ten items including questions assessing positive beliefs (including ‘can improve their language skills with the right help’, ‘can make their parents proud’, ‘can get married when they grow up’, ‘can attend school’ and ‘can play normally with other children’) as well as negative beliefs (including ‘are a public nuisance due to poor hygiene or odd behaviour’, ‘can bring bad luck on the community’, ‘can be seen talking to themselves or shouting outside’, ‘are dangerous to the public because of violent behaviour’, and ‘need to be chained up in the home’). Items were assessed on a 4-point scale ranging from 0 = ‘never’ to 3 = ‘nearly always’.

The social distance questionnaire comprised six items, including ‘would you feel afraid to have a conversation with a child with autism’, ‘would you be upset or disturbed about working with a colleague who is a parent of a child with autism’, ‘would you be unable to maintain a friendship with a parent of a child with autism’, ‘would you feel upset or disturbed about being alone in a room with a child with autism’, ‘would you feel ashamed if people knew a child in your family has been diagnosed with autism’, and ‘would you feel ashamed to be seen out on the street taking care of a child with autism’. Item responses were recorded on a 4-point scale ranging from 0 = ‘definitely not’ to 3 = ‘definitely’, with higher scores indicating a greater preferred social distance from children with autism, suggesting stronger stigmatising attitudes. The survey was first piloted in five untrained HEWs in the Butajira area of SNNPR. Based on the pilot final revisions were implemented before the data collection began.

3.5.2. Potential confounders

Any association between HEAT training and HEW stigma towards child developmental disorders could be confounded by the following: age; religious affiliation; length of work experience practising as HEW; educational achievement in high school; and whether the HEW has a HEAT trained colleague or not.

3.5.3. Data Collection procedures

Data were collected in 2012 and 2013 using pre-tested, structured and semi-structured questionaires for interviewing study subjects (HEWs and caregivers) were used.

Data Collection procedures for sub-study 1

For this sub-study the survey instruments used were prepared in English, translated into Amharic and then back-translated into English to ensure consistency. The instruments were pre-tested by the PI in caregivers of children with ASD and/or ID in attendance at the child mental health clinic at Yekatit 12 Hospital and also in a group of caregivers of children attending the Nehemia Autism Centre, a centre for children with ASD in Addis Ababa. A final version of the questionnaire was established following feedback from the pre-test. Psychiatric nurses were trained to administer the questionnaire by conducting face-to-face interviews with respondents. Training was given over two days to ensure that the psychiatric nurses were familiar with the data collection procedures, the questionnaire, information sheets and consent forms. All questionnaires were checked for completeness, accuracy, clarity and consistency by the PI.

Data Collection procedures for sub-study 2

In this sub-study the questionnaires were prepared in English, translated into Amharic and then back-translated into English to ensure consistency. The instruments used for study 2, including the survey instruments used for evaluating the impacts of training HEWs using basic and enhanced HEAT program interms of change in belief, attitude and social distance were pre-tested in a small group, 5 HEWs in Butajera region. The HEWs included in the actual study were interviewed from the final Amharic version of the survey. Depending on the findings from the pilot, we had altered the wording of some of the questions in the survey.

The data collectors for surveys were women who have completed secondary school (10^{th} grade). Training was conducted over 5 days and focused on good interviewing skills, practice role plays and observed pilot interviews to deliver the questionnaire in a standardized manner.

After identifying the study participants for the study, signed informed consent was obtained.

Data were then collected through a face to face interview using an Amharic version of the structured questionnaires. The interviews were conducted at the Health Sciences College. All questionnaires were checked for completeness, accuracy, clarity and consistency by the candidate.

For in-depth interview of basic HEAT trained HEWs, interviews were conducted in the local language (Amharic) in a private room after obtaining informed consent. With the agreement of participants, the interviews were tape-recorded. Electronic Amharic transcripts were produced and these were translated into English.

Data Collection procedures for sub-study 3

Interview using structured questionnaire was employed for 309 HEWs (104 from HEAT trained group, 97 from HEAT+ trained group and 108 from untrained group). I.e. As described above in objective 2, the instruments were first piloted in a small group, 5 HEWs in Butajira area. Based on these initial pilot interviews, the instruments were revised for the actual study. The questionnaires were administered to HEWs through a face-to-face interview in Amharic by trained and experienced data collectors. This data collection procedure is commonly used in mental health research in Ethiopia and is appropriate for the cultural setting. Data collectors were all women who completed secondary school (10^{th} grade), and were of similar socio-economic status to the participants to limit social desirability bias in the HEWs' responses. Data collectors

were trained over five days; the training focused on good interviewing skills, role plays and observed pilot interviews. The data collection was conducted at the training facilities in Hawassa and Hosanna.

3.5.4. Traning of health extensionworkers

Two types of educational interventions were provided as briefly described above in introduction part: i) the basic mental health module (HEAT), and ii) the enhanced HEAT mental health module (HEAT+) of the upgrading programme for Ethiopia's HEWs. The basic HEAT mental health training materials comprised ten sessions, equivalent to two weeks of fulltime study, and included a focus on mental health management, assessment, and mental illness prevention strategies. One session focused on child development and child mental health, including a discussion of developmental problems. Autism is described only very briefly in two sentences. The HEAT training was provided through class teaching using printed module materials written in English; most students had access to their personal copy of the training materials (85)**.**

The enhanced HEAT training comprised the basic HEAT materials, as well as a DVD and a mental health 'pocket guide'. The DVD included five short video scenarios modelling an HEW interviewing mothers of children with autism or intellectual disability demonstrating skills in early detection, supportive counselling and problem solving. The mental health pocket guide provided a brief introduction to mental health with a main focus on detection, mental health first aid and providing support to affected families. The pocket guide included a dedicated child mental health section, with substantially more (extensive) information on autism and intellectual disability than provided in the basic HEAT materials. The pocket guide was prepared in English and subsequently translated to Ethiopia's official national language, Amharic. The scripts for the video scenarios were written in English, and then translated to and filmed in Amharic. In addition to the basic HEAT materials, HEWs in the HEAT+ group viewed the training videos as part of thier in-class education, and received a personal copy of the pocket guide. Both the basic HEAT materials and the HEAT+ materials are open educational resources, freely available online on the Open University's HEAT website (OpenLearnworks website).

3.6. Data Management and statistical Analysis

3.6.1. Data Management for Sub-study 1, 2 and 3

All collected data of caregivers and HEWs were entered in to computer and double data entry using Epidata version 3(108) was employed to reduce the risk of data entry errors. The data were then exported to SPSS version 23 (122) and MPlus version 5.21 (123) for analysis. Data were anonymised, identifiable through a unique project identification number. A back-up of all data files were carried out on a regular basis.

3.6.2. Data analysis

Data analysis for sub-study 1

Responses to the open-ended question on most needed support were grouped following broad answer categories. The frequency distribution of all closed-ended variables was examined to check for any outliers and to see the overall distribution. The FIS total score was found to be normally distributed, permitting subsequent parametric analyses. Using multiple linear regressions, it was tested whether any of the demographic, clinical or explanatory model and service use related variables could predict FIS sum scores. Non-parametric Mann–Whitney tests were used to examine whether scores on individual stigma items were related to the type of developmental disorder (ID vs ASD). Results were interpreted as significant when $p < 0.05$.

Data analysis for sub-study 2

Quantitative data were entered and cleaned using Epidata version 3 (119). The data were then exported to SPSS version 23 (122) for analysis. The analyses were primarily descriptive. Categorical values were summarized in absolute numbers, and percentages were calculated to one decimal place. Mean and standard deviation was employed for continuous variables. For in-depth interview data, analyses utilized the interview transcripts, interview summaries and the field notes. The English transcripts were analyzed using OpenCode 3.6 qualitative data analysis software (109). A framework analysis was used (110), a common approach in qualitative research that employs several stages: familiarization, identifying the thematic framework, indexing, charting and interpretation. The PI coded all of the transcripts and one of the supervisors (AF) read and gave feedback on the translations, and coding process for possible themes/codes and quotes. An initial list of codes and themes was developed and reviewed and then refined after further re-reading. Illustrative quotes were selected for the resulting themes. The quotes were sufficiently in-depth to allow readers to understand the context of the responses. Finally, the analysed qualitative data were triangulated together with the quantitative findings.

Data analysis for sub-study 3

As in the previous data sets, double data entry using Epidata version 3 (108) was employed to reduce the risk of data entry errors. The data were then exported to SPSS version 23 (111) and MPlus version 5.21 (112) and stata version 13 for analysis. The factor structure of the adapted questionnaires was assessed in two steps, using exploratory factor analyses (EFA) and confirmatory factor analyses (CFA) in MPlus. The total sample of 309 participants was randomly split in half. Half of the sample was used to conduct the EFA. The factor structure suggested by the EFA was subsequently tested employing CFA using the second half of the sample. Modification indices were used as guidelines to examine whether the fit of the resulting model could be further improved. The overall fit of the models was evaluated using the Comparative Fit Index (CFI) and the Root Mean Square Error of Approximation (RMSEA). A good model fit is indicated by CFI values above .90 and RMSEA below .08 (113). Once the best fitting models were identified, further analyses were conducted in SPSS. The internal consistency of the resulting scales was estimated using Cronbach's alpha. Non-parametric Kruskal-Wallis test and subsequent Man Whitney U tests were used to examine group differences in a single item. Analyses of covariance were used to examine group differences in quantitative scales. The following four variables were included as covariates in these analyses: age; length of work experience practising as HEWs age; educational achievement in high school; and whether the HEW worked alongside a HEAT trained colleague.

3.7 Maintaining data quality for Studies 1, 2 and 3

Inorder to ensure data quality, various actions were taken at different levels. First, the questionnaiers were edited and adapted to local language and context. Adaptation was carried out through expert consensus meetings to make the questions directly relevant to autism and appropriate for the Ethiopian context. The questionnaires were translated to the local language (Amharic language) and back translated to English for consistency. A pre-test was made to improve clarity, ordering, and nature of questions. Based on the pre-test, final revisions were implemented before the data collection began. Thorough training of data collectors and supervisors were made before actual data collection; the training focused on good interviewing skills, role plays and observed pilot interviews. On the field, supervisors monitored the conduct of the interview and supported interviewers directly when needed. Close supervision and daily

checking of the questionnaires were made to ensure completeness and consistency. Finally, at the data entry level, data entry clerks and candidate checked for invalid codes, missing values, inconsistency of record and duplicated entries. Double-data entry using Epidata software (108) and consistency checks were employed to reduce the risk of data errors.The psychometric properties of the scales assessing positive and negative beliefs and social distance following adaptation of existing scales was checked and developed.

3.8. Ethical considerations

Ethical clearance and consent

Ethical clearance was obtained from the ethical review committee of the department of psychiatry, Institutional Review Board of the College of Health Sciences and Addis Ababa University and the Open University's Human Research Ethics Committee. Permissions from the regional health bureau and from all respective local administrators were obtained. Participation in the study was completely voluntary, all study participants were informed about the purpose of the study and written informed consent was secured from all participants prior to the start of data collection. Consent was asked in private after the interviewers shared the information sheet with the participant and before any survey questions were administered. In qualitative written consent was obtained from all participants. With the agreement of participants, the interviews were tape-recorded. Electronic Amharic transcripts were produced and these were translated into English, with independent translations to improve reliability.

Data protection

All paper-based records collected in this study were stored in a secure filing cabinet / cupboard. Data relating to personal information of the participants (e.g. their names and contact details) were not be stored on portable devices or media, but only in highly secured systems. Only members of the research group were accessed to the data.

Recompense to participants

HEWs were not remunerated for their participation in the survey, but remunerated for their transportation, perdiem and provided with refreshments. Parents attending Yekatit 12 clinics were not remunerated for their participation in the qualitative interview, although were provided with refreshments in view of the additional time required to complete the interview.

Risk of harm to participants

No risks of harm are foreseen as a consequence of this study. Nevertheless, we were minimise risks by ensuring that participants were fully informed about the study prior to voluntary participation. In the event that a participant wishes to withdraw from contributing their data, they were free to do so. The potential difficulty in connecting with the local health bureaus employing the HEWS were mitigated by working closely with AMREF. Throughout the project we were also maintained close links with the Federal Ministries of Health and Education, to ensure that they were supportive of the project and was supported the implementation of the enhanced mental health study material in the wider HEAT programme.

HEWs (Health extension workers)

To ensure that the HEWs feel free to answer truthfully to the survey, without the risk of their answers or views being shared with their tutor or line manager, we were ensured that no-one outside the research group had access to information that identifies the participants and procedures were clearly explained to the participants.

Parents of children with developmental disorders

We recognized that parents of children with developmental disorders were possibly became distressed when asked about their children's difficulties, or were asked the data collector whether they were blamed for the child's disorder. In all such cases, the parents were gave the opportunity to discontinue the interview and to be able to speak with the on-site child mental health professional about their concerns.

Benefits

This project provides a wealth of knowledge on how to improve mental health awareness in general, and autism awareness and subsequent care for children with autism in particular, in one of the most underserved regions of the world. The HEWs participating in the study benefited directly through the enhanced HEAT mental health materials that were produced as part of this project. It was hoped that families of a child with developmental delay and families affected by mental health problems had benefited indirectly, through increased mental health and autism awareness and the reduction of stigma in their local communities.

Confidentiality

Confidentiality were maintained throughout. Interviews were conducted in private. Confidentiality of collected data were maintained using a secure cupboard in the project office.

Data were anonymised, identifiable through a unique project identification number. A password-protected excel spreadsheet and a separate book (locked up in a different place to the data) were used to link personal identifying details with the project number. A back up of all data files were conducted on a regular basis.

Debriefing

Following the interviews, HEWs and parents were each given a piece of paper which included contact details of the researchers, should they wish to discuss the research subsequently (for example, to remove their data).

3.9 Operational definitions

Childhood mental health care is a care or service given for child hood mental problems or disorder as promotive, preventive and treatment.

Training is a learning process that involves the acquisition of knowledge, sharpening of skill, concepts, rule or changing of attitudes and behaviours to enhance the performance of employees.

A training need is a shortage of skills or abilities, which could be reduced or eliminated by means of training and development.

Health education and training program (HEAT): HEAT is "an accelerated and scalable healthcare education and training programme for frontline healthcare workers". The content of the training is written by African experts with the Open University experts and includes both practical and theoretical training. (http://www.open.ac.uk/about/international-development/ido-africa/HEAT)

Health extension program (HEP) is a community-based health service delivery program whose educational approach is based on the *diffusion model,* which holds that community behavior is changed step by step: training early adopters first, then moving to the next group that is ready to change.

Child developmental disorder: in our study is defined as an umbrella term covering disorders such as intellectual disability as well as autism or ASD. It refers to autism (pervasive developmental disorder) and / or intellectual disability,

Childhood autism is a pervasive developmental disorder that affects children's social, communication and behavioural development.

Intellectual disability is impairment of skills across multiple developmental areas (i.e. cognitive, language, motor and social) during the developmental period. It is impairment of skills

across multiple developmental areas (i.e., cognitive, language, motor and social) during the developmental period.

Stereotypes are assumptions made about a group of people and are applied to individuals irrespective of their personal characteristics because of their affiliation with a certain group. Stereotypes can be positive, negative or neutral.

Positive outcome belief is a thinking that leads to more success/ good outcomes

Negative stereotype: is a stereotype or belief about an individual or group which displays them in a poor light and is normally entirely unrepresentative of the actual situation

Social distance: The desired distance between one societal group and another; measured in this study by ratings of acceptable level of intimacy with a child with autism

Stigma: Stigma refers to attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different.

Unmet needs: unmet needs refers to the needs that a person didn't manage to satisfy yet

Explanatory models (EMs), a term coined by Kleinman, denote the "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (5).

Caregiver is the person who takes primary responsibility for someone who cannot carefully for themselves. It may be a family member including mother and father of child with problem, a trained professional or another individual. Depending on culture there may be various members of the family engaged in care.

Table 1: Summary of study objectives and methods

no	Objectives	Study design	Study-population	Sample size	Data collection	Analytic methods
1	To determine the experience of stigma, explanatory models and unmet need in caregivers of children with developmental disorders.	Cross sectional study design	All caregivers came with treatment for their child	102 caregivers interviwed	Interview based	Descriptive statistics multiple linear regression and non-parametric Mann–Whitney tests
2	To assess training needs and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care in to primary health care services	Mixed comparative cross sectional design and qualitative method	All HEAT trained HEWs that trained at Hawasa and Hosana Health science college	104 HEAT trained HEWs interviewed 11 HEAT trained HEWs in-depth interview	Interview based Indepth interview	Descriptive statistics(frequency, mean, SD) - Frame work analysis approach
3	To evaluate the impact of training HEWs with the basic and enhanced HEAT program on belief, attitudes and social distance in relation to autism.	cross-sectional study design (comparative cross-sectional intervention study)	All HEAT trained, HEAT+ trained and untrained HEWs	309 (108 from untrained HEWs, 104 from basic HEAT trained HEWs and 97 from HEAT+ trained	Interview based	-Descriptive statistics, EFA and CFA - Non-parametric Mann–Whitney tests and kursukal wallis tests -Analysis of covariance test

4. Results

The main findings of this study are summarized under two main sections.

In section 1, findings of sub-study 1 and sub-study 2 are presented. This section details the challenges and unmet need of caregivers of children with developmental disorder and; training needs and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care in to primary health service. In section 2, findings from sub-study 3 are presented. The section describes the impact of basic HEAT and enhanced HEAT program in changing the belief, attitude and social distance of HEWs.

Findings of sub-study 1 and 2

4.1. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders

4.1.1. Demographic characteristics

Data were available for 102 participants. The mean age of the respondents was 36.9 years (SD= 8.9); the majority were Orthodox Christians (n=73; 71.6 %), married (n=70; 68.6%), were urban residents (n=82; 80.4 %) and housewives (n=49; 48.0%). About a fifth of the respondents (n=22; 21.6%) were uneducated; 60.8% (n=62) had received at least some formal education (ranging from any primary (grade 1-8) to any secondary school education (grade 9-12); the remaining caregivers (n= 18; 17.6%) had completed a form of tertiary education. See Table 2. Among the cases, 68 children (66.7%) had a diagnosis of ID and 34 children (33.3%) had ASD as their primary diagnosis. The mean age (SD) of children with developmental disorder was 8.2 (3.3) years. Most of the children (n=77; 75.5%) were male. Of the 102 caregivers of children with developmental disorder, five (4.9%) had one or more other children with developmental problems (Table 2).

Table 2: Demographic and clinical characteristics of the respondents and association with scores on the adapted Family Interview Schedule (FIS) stigma scale, Addis Ababa, 2012/2013

	Characteristic	N (%)	Mean FIS score	Standardised B coefficient	t-value	p-value
Caregiver characteristics						
Age (years)	Mean age 36.9 years					
	<25	9 (8.8)	14.9			
	25-34	30 (29.4)	10.5			
	35-44	41 (40.2)	12.8			
	≥45	22 (21.6)	12.2			
Religion	Orthodox	73 (71.6)	13.9	.21	2.23	.028
	Protestant	16 (15.7)	6.6			
	Muslim	13 (12.7)	9.7			
Marital status	Married	70 (68.6)	11.0			
	Never married	9 (8.8)	11.7			
	Formerly married	12 (11.8)	18.3			
	Not applicable	11 (10.8)	13.5			
Level of education	No formal education	22 (21.6)	13.8			
	Completed grade (1-12)	62 (60.8)	11.6			
	Diploma and above	18 (17.6)	8.4			
Occupation	Farmer	11 (10.8)	9.9			
	Housewife	49 (48.0)	13.2			
	Employed	34 (33.3)	10.7			
	Unemployed	8 (7.8)	13.9			
Residence	Urban	82 (80.4)	12.4			
	Rural	20 (19.6)	11.6			
Child characteristics						
Age of child with developmental disorder	Mean age 8.2 years					
	1-6 years	32 (31.4)	11.4			
	7-12 years	61 (59.8)	11.8			
	13-18 years	9 (8.8)	17.6			
Gender	Boy	77 (75.5)	11.5			
	Girl	25 (24.5)	14.4			
Siblings with developmental problems	No	97 (95.1)	12.3			
	Yes	5 (4.9)	10.8			
Type of developmental disorder	Autism spectrum disorder	34 (33.3)	11.9			
	Intellectual disability	68 (66.7)	12.3			
Caregiver explanatory models						
Supernatural	No	46 (45.1)	9.2			

causal explanation	Yes	56 (54.9)	14.6	.22	2.40	.018
Biomedical	No	41 (40.2)	10.2			
causal explanation	Yes	61 (59.8)	13.6			
First looked for help	Traditional institution	56 (54.9)	10.7			
	Biomedical institution	46 (45.1)	14.0			
Ever sought help from traditional institution	No	34 (33.3)	7.0			
	Yes	68 (66.7)	14.8	.27	2.95	.004
Traditional treatment tried	No	42 (41.2)	8.8			
	Yes	60 (58.8)	14.6			
Biomedical treatment tried	No	61 (59.8)	12.4			
	Yes	41 (40.2)	11.9			

Note: FIS = Family Interview Schedule; the original FIS was adapted to be appropriate for caregivers of children with developmental disorders

4.2.2. Experienced stigma and explanatory models

Caregivers endorsed experience of stigma on many items of the adapted FIS (see Figure 3). For example, 44 out of 102 participants (43.1%) indicated they worried 'sometimes' 'often' or 'a lot' about being treated differently. Likewise, many felt ashamed or embarrassed about their child's condition (n=46; 45.1%), felt a need to hide the problem from people in the community (n=27; 26.4%), or made an effort to keep their child's condition a secret (n=27 out of 101 responses; 26.7%), worried that people would be reluctant to marry into their family (n=25; 24.7%) and worried about taking their child out of the house (n=40; 39.3%). Other experiences of caregivers included feeling depressed about their child's condition (n=71; 69.6%), seeking caregivers of a child with similar problems (n=51 out of 101 responses; 50.5%), feeling that their child's problem is their fault (n=48; 47.1%) and explaining to others that their child does not fit typical cultural stereotypes of mentally ill individuals (n=46; 45.1%) (Figure 3).

The experience of stigma, as indicated by the FIS sum score, was associated with caregivers providing a supernatural causal explanation (p=0.018), but not associated with a biomedical causal explanation (p>0.05). Moreover, experienced stigma was significantly higher in

caregivers of Orthodox Christian faith (p=.028) and in caregivers who had sought help from traditional institutions (p=0.004). Having included 'help sought from traditional institution' in the regression model, the variable 'tried traditional treatments' did not contribute significant additional predictive information (p>.05). Likewise, whether caregivers had ever tried biomedical treatments and whether families first looked for help from a biomedical or traditional institution was not associated with the FIS score (both p>.05). The FIS total score also did not depend on the type of developmental disorder (ID vs. ASD), the child's age or gender, the age or level of education of the caregiver or whether the family lived in a rural or urban area (all p>0.05). Finally, when considering each stigma item in isolation, no difference in reported stigma was found in relation to type of developmental disorder (all p>0.05).

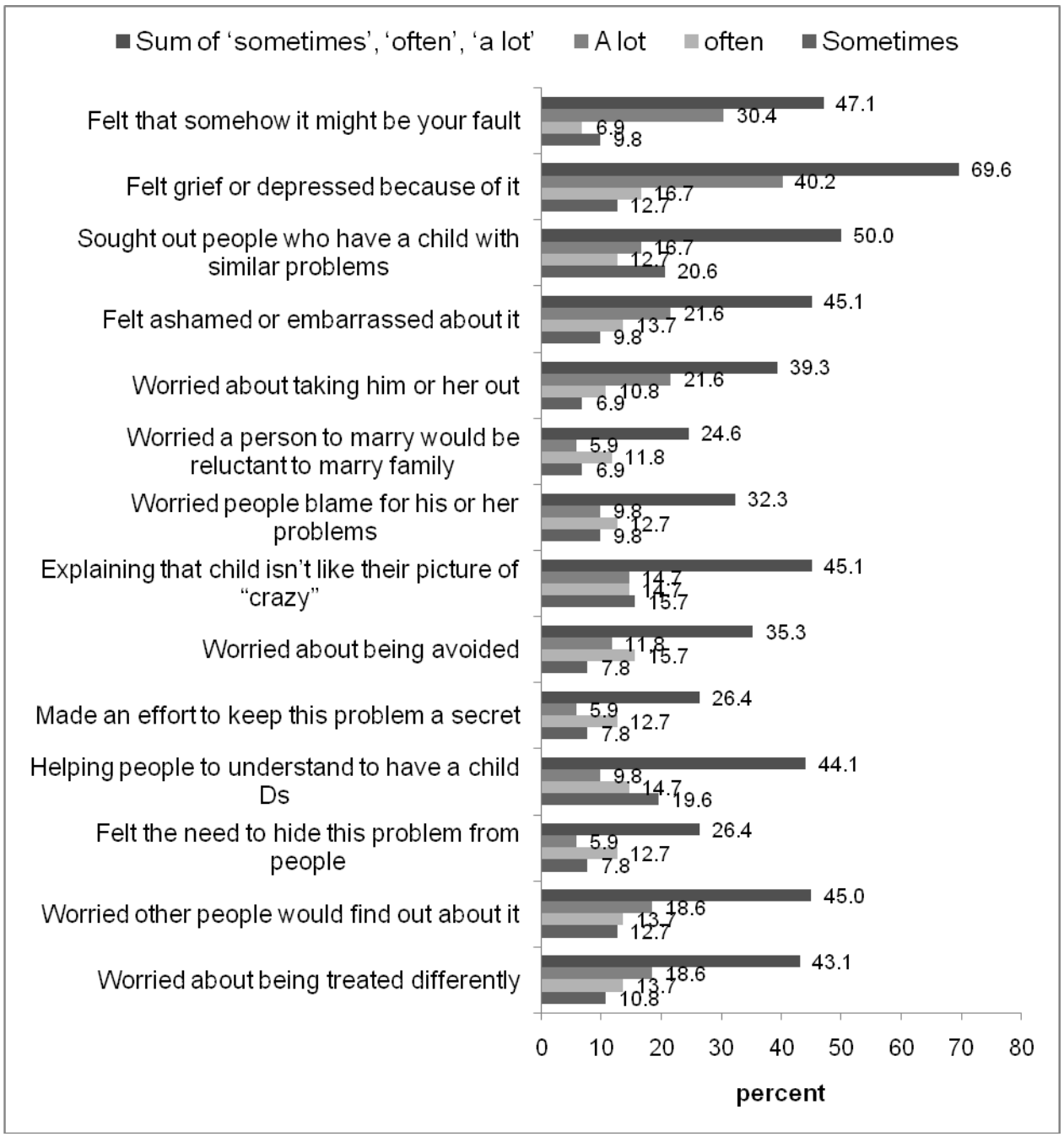


Figure 3: Pattern of positive responses on the Family Interview Schedule questionnaire in caregivers of children with developmental disorders, Addis Ababa, Ethiopia, 2012/13.

Note: Proportion of participants responding 'sometimes', 'often' or 'a lot' to each of the items, and the summed response to any of these three categories is presented in the figure. The remaining item responses concerns the response 'not at all'.

Caregivers cited a mixture of biological and supernatural factors as causes for their child's condition (Table 3). The most common biomedical explanations were head injury (n = 31; 30.4 %), birth complications (n = 26; 25.5 %), epilepsy (n = 21; 20.6 %), pathogens (n = 12; 11.8 %) and a family history (n = 12; 11.8 %). Frequently cited supernatural explanations included spirit possession (a spirit taking control over one's thinking and actions; n = 41; 40.2 %), a sinful act (a direct result of the caregiver's transgression n = 28; 27.5 %), punishment from God (specific attribution of the consequence of a sinful act to punishment from God n = 26; 25.5 %), evil eye or "buda" (a spell cast by the eye, inflicting injury or misfortune on the person being looked at; n = 20; 19.6 %), and curse or bewitchment (harm inflicted by magical acts or supernatural powers instigated by another person or by supernatural beings; n = 10; 9.8 %). Over half (n = 56; 54.9 %) of respondents gave at least one supernatural causal explanation, while 59.8 % (n = 61) gave at least one biomedical explanation. Biomedical and supernatural causal explanations were not mutually exclusive, with 37 participants (36.3 %) providing both biomedical and supernatural explanations.

Table 3: Caregiver perceived causes of developmental disorder in the child, Addis Ababa, 2012/13*

Perceived causes of child developmental disorder	**Number**	**Percent**
Spirit possession	41	40.2
Sinful act	28	27.5
Punishment from God	26	25.5
Epilepsy	21	20.6
Evil eye	20	19.6
Family history	12	11.8
Pathogen / infectious cause	12	11.8
Curse / bewitchment	10	9.8
Head injury	31	30.4
Birth complications	26	25.5
Drinking alcohol in pregnancy	3	2.9
Chewing *Catha edulis* (khat) in pregnancy	2	2.0

***** Respondents could provide multiple answers

Even though the majority (n=69; 67.6%) of participants believed that their child's developmental problems were very or quite severe, most of the respondents (n=94; 92.1%) believed that their child's problems could be cured.

Only a minority of respondents thought that their child's condition could be transmitted to other people (n=7; 6.9%). A slightly higher number (n=12, 11.8%) indicated that other people thought their child's condition was contagious (Table 4).

Table 4: Caregiver perceptions about the child with a developmental disorder, Addis Ababa, Ethiopia, 2012/13

Variable	Number	Percent
Believe that child's problems with autism/ID can be cured		
Yes, cured	94	92.2
Not cured, but improved	8	7.8
No cure or improvement	0	0
How severe do you think your child's problem with developing slowly is?		
Very severe	44	43.1
Quite severe	25	24.5
Not too severe	25	24.5
Not severe at all	8	7.8
Do you think your child's condition can be transmitted to other people?		
No	95	93.1
Yes	7	6.9
Do you think other people think that your child's condition can be transmitted to other?		
No	90	88.2
Yes	12	11.8

4.1.3. Traditional and biomedical support sought

When asked where they went to seek help for their child, more than half of the caregivers indicated they first sought help from traditional places (n=56; 54.9%), while just under half of the participants first approached a biomedical institution (n=46; 45.1%). When asked what other types of help they had sought prior to coming to the current child mental health clinic, the majority had attended a hospital (n=83; 81.4%) and/or a private clinic (n=27; 26.5%), and many had visited traditional institutions, including centres for religious healing (e.g. holy water (n=53; 52.0%), a church or priest (n=35; 34.3%)) or different types of traditional healers (n=68; 66.7%) (Table 5).

Table 5: Source of help for child with a developmental disorder, Addis Ababa, Ethiopia, 2012/13

Help-seeking	Number	Percent
First place where help sought		
Biomedical (modern health institution)	46	45.1
Traditional	56	54.9
Have you ever looked for help from any of the following*		
Holy water	53	52.0
Church / priest	35	34.3
Debtera (spiritual healers in Orthodox Christian clergy)	7	6.9
Herbalist	11	10.8
Mosque	9	8.8
Kalicha (spiritual healers in Muslim clergy)	6	5.9
Tanquaye (Sorcerer)	5	4.9
Wogesha (traditional physical therapy including massage and bone setting)	5	4.9
Hospital	83	81.4
Private clinic	27	26.5
Public health centre	22	21.6
Health extension workers	6	5.9
Private pharmacy	6	5.9
Broad classification of help sought*		
Traditional help sought	68	66.7
Biomedical help sought	88	86.3

Note: * Respondents could provide multiple answers

4.1.4. Type of interventions tried

Caregivers reported using both biomedical treatments (tablets (n=40; 39.2%) or injections (n=4; 3.9%) received through a health facility) and traditional interventions (prayer (n=48; 47.1%), *kitab* (a written script tied on the arm or neck; n=8; 7.8%), slaughtering a sheep as a sacrifice (n=4; 3.9%), or fumigating (making excessive use of smoke by burning incense; n=2; 2.0%)) as treatment interventions. A subgroup of caregivers also indicated they had used beating (n=19; 18.6%) or chaining (n=9; 8.8%) to manage their child (Table 6). Many (n= 27, 26.5%) caregivers had tried both traditional and biomedical treatment for their child (Table 6).

4.1.5. Unmet need

The most common unmet needs expressed by caregivers were appropriate educational provision for their child (n=76; 74.5%), treatment by a health professional (n=48; 47.1), financial support (for instance to buy food) (n=31; 30.4%), access to support from professionals in managing their child and supporting their child's skills development (n=28; 27.5%) and access to expert information and advice about their child's condition (n=23; 22.5%) (Table 6). All responses concerned desired support from outside rather than within the family.

4.1.6. Coping strategies

Various coping mechanisms, including talking to someone, seeking religious help and using substances/drugs, were used to deal with emotional difficulties arising as a result of caring for a child with ASD or ID. Caregivers most often spoke to a health professional (n=88; 86.3%), talked to family members (n=87; 85.3%) or talked to friends (n=78; 76.5%), and also often used prayer (n=59; 57.8%) as a coping strategy. Adverse coping strategies such as chewing *Catha edulis* (khat) (n=5; 4.9%), drinking alcohol (n=4; 3.9%) and smoking cigarettes (n=3; 2.9%) were used by a minority of respondents (Table 6).

Table 6: Type of treatment tried*, help most needed* and coping mechanisms* of the caregivers of children with developmental disorders, Addis Ababa, Ethiopia, 2012/13

	Number	Percent
Type of treatment tried*		
Tablets from health facility	40	39.2
Injection from health facility	4	3.9
Chaining	9	8.8
Beating	19	18.6
Fumigating	2	2.0
Prayer	48	47.1
Slaughtering a sheep	4	3.9
Kitab (a written script tied on the arm or neck)	8	7.8
Help most needed*		
Educational provision for their child	76	74.5
Treatment by a health professional	48	47.1
Access to support from professionals in managing their child and/or supporting their child's skills development	28	27.5
Financial support (e.g. to buy food)	31	30.4
Access to expert information and advice about their child's condition	23	22.5
Help sought to cope with child's condition*		
Talking to family	87	85.3
Talking to friends	78	76.5
Talking to health professional	88	86.3
Prayer	59	57.8
Drinking alcohol	4	3.9
Chewing khat	5	4.9
Smoking cigarettes	3	2.9

* Respondents could provide multiple answers

4.1.7. Gateway to the clinic

The most common source of information that had led the family to attend the child mental health clinic was a community-based health extension worker, with 52.9% of caregivers citing their help in finding the way to the clinic (Figure 4).

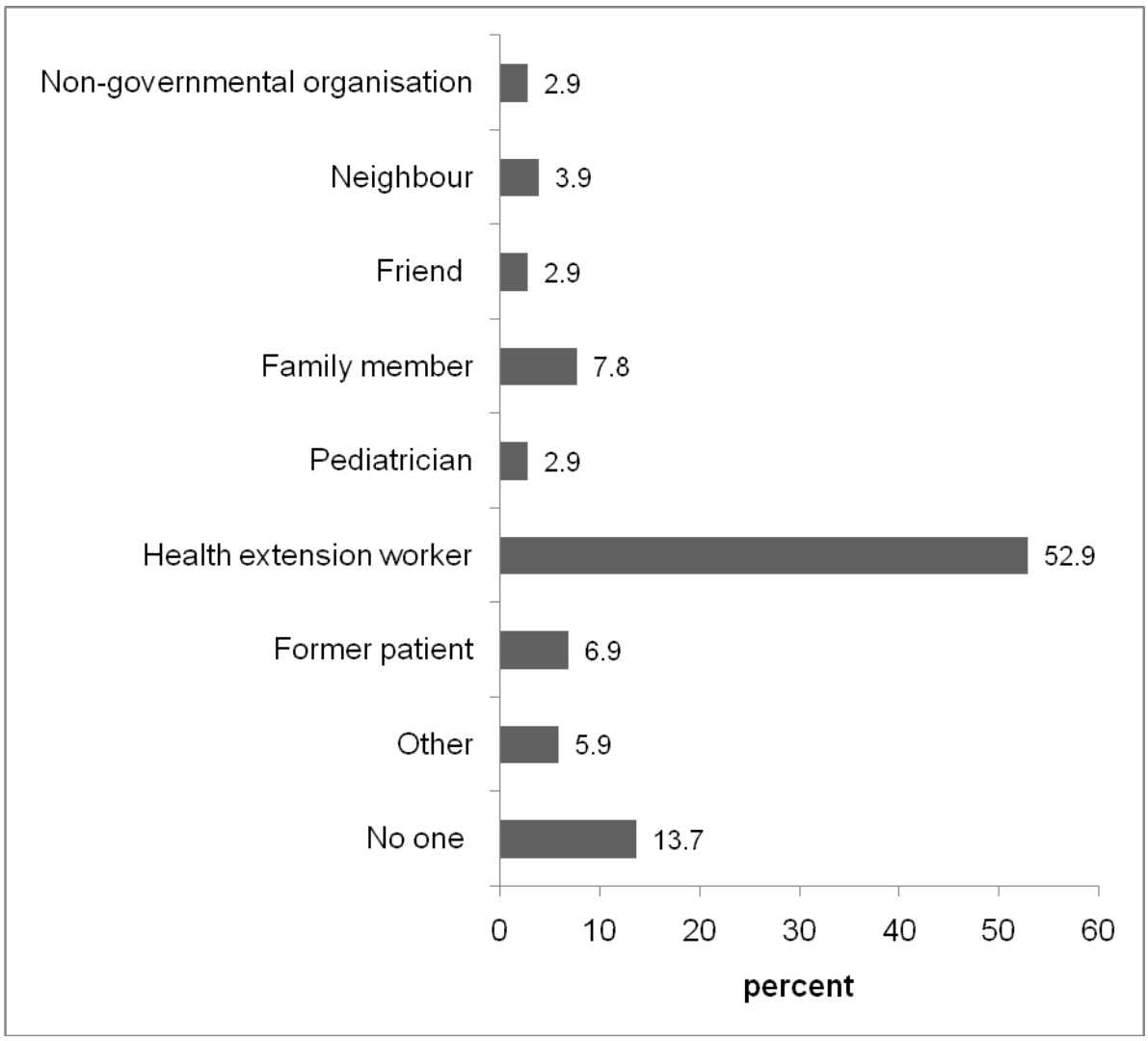


Figure 4: Source of information leading to attendance of caregiver at child mental health clinic, Addis Ababa, Ethiopia, 2012/13

4.2. Training needs and perspectives of health extension workers in relation to integrating child mental health care in to primary health care services

4.2.1. Socio-demographic characteristics of the respondents

A total of 104 HEAT trained HEWs were included in the analyses. All HEWs were female and their mean age was 25.8 years (SD 3.5). Most of the participants were either protestant (67.3%; n=70) or Orthodox Christian (19.2%; n=20) in religion (Table 7). The HEWs were employed for about 76 months on average at the time of the study, but they were surveyed only about four months after their HEAT training (Table 7).

Table 7: Background characteristics of HEWs, SNNPR's, Ethiopia, 2012/13 (n = 104)

Socio-demographic characteristics	Frequency	Percentage
Religious affiliation		
Muslim	12	11.6
Orthodox Christian	20	19.2
Catholic	2	1.9
Protestant	70	67.3
Highest grade you completed at school		
Grade 10	69	66.3
Grade 12	35	33.7
Age in years (Mean ±SD)	25.8 ±3.5	
Overall mean±SD **month work experience as HEW**	75.7 ±13.6	
Mean±SD **month work experience at current post**	69.7±20.1	

4.2.2. Learning needs of HEWs

All HEWs surveyed considered the topic of child mental health to be important or very important (n=104). Most of the HEAT-trained HEWs (88.5%; n=93) reported that they were interested in the study modules focusing on childhood mental health problems (Table 8). The perceived quality of all mental health study texts (i.e., not only child mental health) was average or above average (76.9%, n =80) with 23.1%, n=24 perceiving it to be below average. Nineteen HEWs (18.3%) did not have access to the study materials. Most of these (53%) who did not have access to the study materials rated the materials as below average while only 16% of those who had the study materials rated the materials as below average.

The in-depth interviews largely reinforced the above views. However, some participants expressed that important concepts about child mental health problems, especially on child developmental disorders, were not covered adequately.

"[…] I think there is nothing missing from the contents of the modules on adult mental disorders. However, training on mental health needs of children lacked many things. The module […] covered very little on child developmental disorders and autism. It would be better to include the symptoms of developmental disorders, including autism, and details on how to make diagnosis, identify causes and provide treatment. The other problem was that the original teaching materials [on mental health] were not available and we had to make copies [for our use]." (HEW 5).

Regarding the importance of the subject of child mental health problems, one participant stated:

"[…] Generally the training was very important; I gained knowledge about developmental disorders…When I compare myself from previous, I learned many things […] after training I learned how to treat, identify and manage childhood mental problems." (HEW 1).

Table 8: Attitude toward training and training materials by HEWs, SNNPR, Ethiopia, 2012/13 (N= 104)

Variables	Frequency	Percentage
Access to training materials		
Yes	85	81.7
No	19	18.3
Opinion of quality of study material		
Extremely poor	14	13.5
Below average	10	9.6
Average	33	31.7
Above average	17	16.4
Excellent	30	28.8
Overall, did you find the mental health and childhood problems study text interesting to study?		
Not at all interested	5	4.8
Of little interest	7	6.7
Moderately interesting	35	33.7
Interesting	18	17.3
Very interesting	39	37.6
Do you feel that the topic of childhood behavioural and developmental problems is important for a HEW?		
Not at all important	0	0
Of little importance	0	0
Moderately important	0	0
Important	4	3.8
Very important	100	96.2

4.2.3. Experience and role of HEWs

Nearly half of the trained HEWs (46.1%; n=48) reported that they made use of the mental health training modules, which included the child mental health section, once or twice a week (Table 9). The in-depth interviews revealed challenges in their experience of using the training materials.

> *"[…] Instruction in the English language was difficult to understand [...] In addition, as this was a new course, my previous limited training and knowledge about child developmental disorder made it very difficult to understand child mental disorders." (HEW 1).*

The other participants also emphasized the problem:

> *"There is language problem […] Even the few things we understood about adult mental problems was because the instructor translated his lecture into Amharic (the local language) during his teaching. The child mental health session was not clear and has only limited contents with very little [information] on autism. So, we need to learn in detail about each kind of the disorder with simple language." (HEW 2).*

When the respondents were asked about how the training and training materials helped in their daily work, most reported benefits as improvement in knowledge and awareness, case identification and provision of service (Table 9). Qualitative study participants confirmed similar benefits of training: as a gain in knowledge, skills, a positive attitude and confidence. For example, one participant stated:

> *"... After training I gained knowledge, [was] able to detect child mental disorders, including autism, motivated me to give health education to raise awareness of the community about misconceptions [for example] not to hide child with developmental disorder, negative attitudes, and stigma and able to refer cases to hospital and advice on care and support." (HEWs 9).*

On the other hand, many of the participants reported having poor knowledge and said that they were unable to distinguish autism from the other types of child mental disorders. They also lacked the skills and confidence to identify, treat and refer child mental health problems.

> *"I heard about autism for the first time [when you ask this question], we did not learn [about autism] during the training of two weeks period on how to offer advice, support*

and prevent or treat […] a child with developmental disorders *or parents or family." (HEW 11).*

Most also said they were fearful and embarrassed about approaching and helping families with an affected child and that their negative attitude might have been a barrier towards providing to children with development problems.

"[…] the other problems that affected doing this work were my own fear and misperception that the family may not accept my advice and my belief that such cases could not be cured or have treatment." (HEW 3).

"[…] my negative attitude and misperception towards improvement of children with developmental disorder is a problem towards helping a child with mental problem. (HEW 9).

About one third (35.6%, n=37) of HEWs reported that they had organized a mental health awareness meeting in their community (Table 9). Moreover, many other participants reported little activity at their work place because of their poor competency and health institution constraints such as lack of knowledge and skill of PHC workers at health centers, large coverage area and overload of work, problem of transport, lack of supportive supervision and coordination. The activities performed by HEWs were identification, counselling, awareness raising, organizing community meetings, provision of direct services, referring and follow up and monitoring during home visits.

Table 9: Experience of HEWs in utilization of the training materials and organizing a mental health awareness meeting program, SNNPR, Ethiopia, 2012/13

Variables	Frequency	Percentage
Do you use any of the training provided in the mental health and childhood problems study material in your work?		
No, never	14	13.5
Yes, but only rarely (once or twice a year)	19	18.3
Yes, sometimes (about once a month)	23	22.1
Yes, often (about once a week)	20	19.2
Yes, very often (more than once a week)	28	26.9
If Yes, how did the training help you in your daily work? *		
Increasing knowledge and awareness	52	50.0
Improve the service	22	21.2
Identification of the case	14	13.5
Motivated me to do and read the materials	8	7.7
Counseling	8	7.7
Referral	6	5.8
Have you organized a mental health awareness meeting in your community?		
No, never	67	64.4
Yes, but only once	26	25.0
Yes, two or more meeting	11	10.6

***** Respondents could provide multiple answers

4.2.4. Rationale for training

All HEWs reported a high level of need for training on identification and treatment of child mental health problems. Most of HEAT trained HEWs said that child mental problems were very common in the community and had a huge impact on the family and individual. The impacts were mostly perceived to be related to financial, social and health related burdens. The social burden mentioned by the participants were related to the child's behavioural difficulties, carers being unable to work and being limited in their ability to participate in social activities because of needing to be the carer, negative attitudes from the community and stigma. Economic burden on families, such as the cost of transport and treatment was also reported by HEWs. Most of the HEWs interviewed in-depth thought that the caregivers' burdens were aggravated by the lack of availability of treatment at PHC and poor awareness, negative attitudes and stigma from the community about the condition.

> *"[…] there are many children with developmental disorder in the community; for example, on my kebele I have identified 4 cases, all of the children do not speak even*

*when they are hungry [...]. I gave advice for the family on hygiene and appropriate diet for the families of children with such problems […]." (*HEW 8*).*

"[…] Financial problem of the family for treatment of child with developmental disorder after referral was challenge that hinder my day to day work improvement […] other problems are lack of other service and resource…for example, special school to educate these children….and lack of trained health personnel to help child and family at health center of rural area are the most important problems. So, treatment, care and support need to be found and improved at health center […]." (HEW 4).

"[…] the other problem was negative attitude and misperception of the community and family about treatment and cause during counselling and awareness raising for referral to hospital i.e. belief of the community that these kinds of conditions do not need modern treatment and can be transmitted to others. Belief that cause is from God's punishment and treatment is only through traditional or religious treatment such as praying, holy water, spiritual belief etc […]." (HEW 5*).*

The HEWs also reported a need for further training due to their low level of baseline competency in the identification of affected children, to provide interventions and awareness of referral services. They recognized a need to improve motivation across all HEWs to provide this service. They also recognized a need to improve quality of care and safety of families and the affected individual. The majority of HEWs reported that, as they were already delivering different packages of home-based care for mothers and children, they would easily be able to identify and treat the children if they acquired adequate knowledge and skills. For example, one HEW stated as follow;

"[…] not know how we identify child mental health problems in practice […] This is a new course, better if we get help in practice for diagnosis/identification of cases because we were not exposed to autistic cases in practice." (HEW 7).

HEWs reported the need for expanded in-service training. When asked to suggest specific content to be included in child mental health training, the most commonly reported training need was for detailed, clear and separate training on child developmental disorders (74.1%, n=77)

(Table 10). Almost all of the in-depth interview participants wanted in-service training, especially in the identification, causes, prevention and treatment of child mental health problems, including developmental disorders.

The most important unmet need on methods of training was preparation of a detailed, clear and separate module (74.0%, n=77) and practical training mostly on how to give practical support including first aid to families with child mental health needs (21.2%, n=22) (Table 10). In-depth interviews also indicated similar training needs. One HEW said;

> *"We are giving service at the grass root level and in the community, so we need to be up to date with the new information and advance in our knowledge and skill for detection, treatment and referral. Then we can share and provide appropriate service for model family and community/family but we didn't get this opportunity. […] my suggestions as a means of improvements are refresher courses (in-service training) […] about developmental disorder." (HEW 7).*

Table 10: Training needs of HEWs on child mental health problems*, SNNPR, Ethiopia, 2012/13 (n = 104)

Variables	Frequency	Percentage
Suggested area to be included in child mental health problems study text*.		
Detailed, clear and separate session	77	74.1
signs, symptoms and cause or detail on identification	20	19.2
Management and treatment	16	15.4
More practical part i.e. about first aid	11	10.6
Suggestions on how study text can be improved*		
Detailed, clear and separate module	77	74.0
practical training	22	21.2
Simple Amharic	7	6.7
Receiving module on time	8	7.7
Adequate time for training	6	5.8

***** Respondents could provide multiple answers

4.2.4. Barriers to integration of child mental health care

Many barriers were reported to affect the integration of child mental health care into existing routine care. The identified barriers were at the level of the HEW, community and institution.

The barriers at the level of the HEW included poor knowledge and skills, negative attitudes and stigma and demotivation. The barriers at the community level were misconceptions, negative attitudes, stigma and discrimination. This is stated by one participant as quoted below;

> *"[…] lack of adequate knowledge and skill on child developmental disorders also minimized my confidence in helping family. Negative attitude and misperception of the community and family had also decreased our motivation to help […]." (HEW 5).*

Two HEWs described how disease attributions may be barriers encountered within a family:

> *I have got one child in our survey; he does not talk. His parents were hiding information about him. They thought that this type of disease is cured through traditional or spiritual means. They said [his illness was] due to spirit possession-likift-because someone had given him some potion. When I saw the child, he was very pale and […] chained. Then I started to discuss how this child should be treated […] but parents said if this child got medical treatment he may die; instead traditional treatment like slaughtering [an animal] and praying were preferred treatment. Finally, we planned another appointment for further intervention and discussion about referral of the child." [HEW 2].*

> *"[…] at the beginning, he (father) became resistant because of his strong belief that [the child's] condition was not curable through modern treatment because it was the result of punishment from God and that this child could only be treated by holy water." [HEW 3].*

In addition, low expectation of community and family of input from HEWs, and lack of appreciation from community leading to demotivation of HEWs, were also mentioned as barriers.

> *"Widespread negative attitude and misperception of community and family on treatability of child with developmental disorders after treatment and the feedback of community or family would have a demotivating effect on me to do more work on the problems." (HEW 9).*

Institutional barriers such as constraints of resources, including lack of trained health professionals at health centers, lack of services and facilities and financial problems for transport, treatment and other costs, were common barriers mentioned by HEWs. Minimal

attention by stakeholders or government bodies, lack of supportive supervision**,** coordination and collaborative work were also mentioned as constraints. The other barriers for integration of the mental health service into routine practice were insufficient training due to inadequate time allocation, content, methods and scope of training, minimal attention on mental health by tutors, inaccessibility of the module and other reference materials, and heavy work load.

> *"[…] lack of health service (treatment, care and support) and special school to help these children and their families in rural area are the most important barriers. Constraints of time because of overload of work are also another barrier. So, care and support including treatment need to be improved." (HEW 4).*

Other HEWs also explained that when there are no skilled professionals to provide care at the health centers or family cannot afford to take their child to a health centre, this limited the acceptability of the care they can provide.

> ***"****Lack of skilled health professional to help children at health center after referral and economic problem of parents to accept referral also reduces our acceptability." (HEW 5).*
>
> *"Ignorance of the community and lack of attention from government are also some of the problem that needed to be solved." (HEW 9).*

4.2.5. Facilitating factors to overcome barriers for integrating child mental health care

Most respondents considered child mental health problems as important and had positive attitude and interest toward training and providing care for children with mental health problems. The other facilitating factors reported were availability and the use of reference materials provided as part of the HEAT training. High motivation and willingness of HEWs to apply and maintain an effort in their task, positive attitude and suggestion of HEWs to integrate the child mental health care into routine general health service were also mentioned as facilitating factors for integrating child mental health service. Some HEWs were identifying child mental problems and getting involved in the actual service delivery of child mental health care. One participant explained the benefits as:

> *"There is change in my knowledge and skill and training helped me to plan, to do survey for detection or diagnosis of cases. It also helped me in mobilizing community for support and detection of cases easily because people know where the child with mental problems*

including autism are found i.e. they [community] can easily identify in which house a child with autism is living." (HEW 2).

The organizational structure of the district and the work of HEWs with families was considered as an important facilitator.

"[…] Working on child mental health problems is not problematic or a challenge, because our work is mostly with mothers; so, we can easily access children with no [no extra work] overload. This work is very important because children are the future generation of the country. (HEW 7).

HEWs also suggested many facilitators to overcome barriers for integrating child mental health care. The suggested facilitators for addressing the barriers in performing tasks and integrating service of child mental health care were in-service training for HEWs and general health staff and awareness raising programmes using mass media for those in positions of authority and stakeholders. Expanding availability of services in the health sector, school setting and other settings were also suggested for the improvement of care for the child and family. Facilitating referral linkage, coordination of activity, integration and collaboration of work and continuous supportive supervision were also suggested. The other most important suggestions to address barriers were practical exposure to mental health problems during training and improvement of the contents, methods and scope of training. Concerning this issue, one of the HEWs said;

"Accessibility and availability of information and child mental health service for children, family and community about child DD and child mental health care are mandatory. In addition, in-service training for all HEWs that did not receive HEAT training should be given i.e. every HEW should get the chance of learning on how to detect (diagnose), treat and help children with DD, their families and community. For example, in our kebele there are more than 200 house holds; I can't cover all these households on my own, so my friend (HEW in the same kebele) also needs to get this training [HEAT training] to improve treatment, care and support." [HEW 4].

Another participant said *"[…] In order to increase awareness-raising, motivation and advocacy on child mental problems, attention needs to be given for integrated work, involvement of all*

important stakeholders, for example, administrators, religious leaders and other stakeholders. So, help and integration from other stakeholders are mandatory to bring change, to solve the problems of the individual, family and community and prevent further burden." (HEW 5).

Findings of sub-study 3 (evaluation of impact)

4.3. Impact of training health extension workers on belief and attitude toward children with autism

4.3.1. Socio demographic characteristics

All HEWs were female. The sample characteristics for each of the three groups are reported in Table 1. The three groups had a similar distribution of religious affiliations; similar proportions in each group had completed high school to 10^{th} or 12^{th} grade level, and similar proportions worked alongside a HEW colleague who had already completed the upgrading programme. The HEAT group was significantly older and had a significantly longer experience working as an HEW compared to the HEAT+ and untrained groups ($p < .01$). Moreover, the untrained group had a slightly higher average grade in high school than the HEAT trained group ($p < .01$). No other group differences in background characteristics were observed.

Table 11: Socio demographic characteristics of the HEWs included in each of the three study groups, SNNPR's, Ethiopia 2013, (n=309)

Characteristic	Untrained	HEAT trained	HEAT+ trained
Mean age (years)	25.6 ±3.3	27.0±3.5*	25.4 ±3.5
Mean work experience (months)	78.1 ± 19.2	86.9±19.4*	78.7±17.7
Religious affiliation	N (%)	N (%)	N (%)
Muslim	11 (10.2)	13 (12.5)	6 (6.2)
Orthodox Christian	11 (10.2)	19 (18.3)	24 (24.7)
Catholic	3 (2.8)	2 (1.9)	1 (1.0)
Protestant	83 (76.9)	69 (66.3)	65 (67.0)
Other	0 (0)	1 (1.0)	1 (1.0)
HEAT-trained colleague employed in same community	N (%)	N (%)	N (%)
No	102 (94.4)	96 (92.3)	92 (94.8)
Yes	6 (5.6)	8 (7.7)	5 (5.2)
Mean of mark in high school	2.25 ±0.29	2.13±0.26[$]	2.21±0.26
Grade they completed at school	N (%)	N (%)	N (%)
Grade 10	73 (67.6)	63 (60.0)	71 (73.2)
Grade 12	35 (32.4)	42 (40.0)	26 (26.8)

* significantly different from other two groups, $p < 0.01$ [$] (not explained)

4.3.2. Characteristics of instrument (Factor analyses)

The ten items assessing positive and negative beliefs towards children with autism were examined using EFA. Initial EFA indicated that one item showed little covariance with the other nine items. Item content inspection ('Can improve their language skills with the right help') suggested this item mainly assesses a positive belief in efficacy of an intervention, rather than a positive belief towards children with autism directly. The EFA was re-run including the nine remaining items only. The results indicated a 2-factor structure: one factor comprising four positive belief items, and one factor comprising five items assessing negative beliefs. This 2-factor model was subsequently fitted to the second half of the data. Inspection of the modification indices suggested the fit could be improved by allowing cross-loading of one positive belief item on the negative belief factor. Implementing this modification resulted in a good model fit (CFI= 0.927; RMSEA = 0.064). Next, the six items assessing social distance were subjected to EFA. The EFA suggested a 1-factor structure; testing this structure using CFA in the second half of the data indicated a very good model fit (CFI= 0.987; RMSEA = 0.063); there were no modification indices above the minimum value. The 4-item positive beliefs scale had moderate internal consistency (Cronbach's $\alpha = 0.54$), acceptable when taking into account the low number of items included. The internal consistency of the 5-item negative beliefs scale ($\alpha = 0.67$) and 6-item social distance scale ($\alpha = 0.72$) were adequate.

4.3.2. Impact of training on beliefs and attitudes

4.3.2.1. Item-by-item responses of the participants' positive and negative belief and social distance

Tables 12 and 13 show the item-by-item responses of the participants in relation to positive (Table 12) and negative (Table 13) beliefs and stereotypes towards children with autism, while Table 14 presents the responses related to preferred social distance.

Item-by-item responses of the participants' positive belief

Table 12: positive belief in effect language intervention and positive beliefs towards children with autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

Items	Untrained	HEAT trained	HEAT+ trained
	N (%)	N (%)	N (%)
Single item: positive belief in effect language intervention			
Can improve their language skills with the right help			
Never	24 (22.2)	6 (5.7)	4 (4.1)
Rarely	45 (41.7)	18 (17.1)	12 (12.4)
Often	19 (17.6)	26 (24.8)	39 (40.2)
Nearly always	20 (18.5)	54 (51.4)	42 (43.3)
Positive beliefs scale			
Can make their parents proud			
Never	60 (55.5)	77 (74.1)	84 (86.6)
Rarely	14 (13.0)	20 (19.2)	5 (5.2)
Often	20 (18.5)	5 (4.8)	5 (5.2)
Nearly always	14 (13.0)	2 (1.9)	3 (3.0)
Can attend school			
Never	54 (50.0)	39 (37.5)	51 (52.6)
Rarely	38 (35.2)	46 (44.2)	41 (42.3)
Often	8 (7.4)	14 (13.5)	3 (3.1)
Nearly always	8 (7.4)	5 (4.8)	2 (2.0)
Can get married when they grow up			
Never	59 (54.6)	37 (35.6)	46 (47.4)
Rarely	38 (35.2)	49 (47.1)	35 (36.1)
Often	7 (6.5)	14 (13.5)	11 (11.3)
Nearly always	4 (3.7)	4 (3.8)	5 (5.2)
Can play normally with other children			
Never	65 (60.2)	65 (62.5)	68 (70.1)
Rarely	28 (25.9)	26 (25.0)	25 (25.7)
Often	9 (8.3)	6 (5.8)	2 (2.1)
Nearly always	6 (5.6)	7 (6.7)	2 (2.1)

Item-by-item responses of the participants' negative belief

Table 13: Negative beliefs and stereotypes toward autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

Items	Untrained	HEAT trained	HEAT+ trained
	N (%)	N (%)	N (%)
Are a public nuisance due to poor hygiene or odd behaviour			
Never	12 (11.1)	7 (6.7)	37 (38.1)
Rarely	45 (41.7)	39 (37.5)	29 (29.9)
Often	26 (24.1)	32 (30.8)	22 (22.7)
Nearly always	25 (23.1)	26 (25.0)	9 (9.3)
Can bring bad luck on the community			
Never	24 (22.2)	47 (45.2)	65 (67.0)
Rarely	39 (36.1)	36 (34.6)	21 (21.6)
Often	28 (25.9)	4 (3.9)	5 (5.2)
Nearly always	17 (15.8)	17 (16.3)	6 (6.2)
Can be seen talking to themselves			
Never	10 (9.3)	7 (6.7)	34 (35.1)
Rarely	19 (17.6)	45 (43.3)	37 (38.1)
Often	43 (39.8)	29 (27.9)	16 (16.5)
Nearly always	36 (33.3)	23 (22.1)	10 (10.3)
Are dangerous to the public because of violent behaviour			
Never	20 (18.5)	20 (19.2)	46 (47.4)
Rarely	32 (29.6)	40 (38.5)	36 (37.1)
Often	38 (35.2)	23 (22.1)	7 (7.2)
Nearly always	18 (16.7)	21 (20.2)	8 (8.3)
Need to be chained up in the home			
Never	77 (71.3)	102 (98.1)	96 (99.0)
Rarely	11 (10.2)	2 (1.9)	1 (1.0)
Often	9 (8.3)	0 (0)	0 (0)
Nearly always	11 (10.2)	0 (0)	0 (0)

Item-by-item responses of the participants' social distance

Table 14: Social distance towards children with autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

Items	Untrained N (%)	HEAT trained N (%)	HEAT+ trained N (%)
Feel afraid to have a conversation with a child with autism			
Definitely not	42 (38.9)	75 (72.1)	87 (89.7)
Probably not	8 (7.4)	7 (6.7)	3 (3.1)
Probably	26 (24.1)	9 (8.7)	4 (4.1)
Definitely	32 (29.6)	13 (12.5)	3 (3.1)
Upset about working with a colleague who is a parent of a child with autism			
Definitely not	55 (50.9)	85 (81.7)	84 (86.6)
Probably not	14 (13.0)	5 (4.8)	7 (7.2)
Probably	18 (16.7)	11 (10.6)	3 (3.1)
Definitely	21 (19.4)	3 (2.9)	3 (3.1)
Able to maintain a friendship with a parent of a child with autism*			
Definitely not	50 (46.3)	19 (18.2)	10 (10.3)
Probably not	13 (12.0)	6 (5.8)	3 (3.1)
Probably	7 (6.5)	11 (10.6)	1 (1.0)
Definitely	38 (35.2)	68 (65.4)	83 (85.6)
Feel upset or disturbed about being alone in a room with a child with autism			
Definitely not	39 (36.1)	61 (58.6)	68 (70.1)
Probably not	10 (9.3)	10 (9.6)	14 (14.4)
Probably	25 (23.1)	19 (18.3)	9 (9.3)
Definitely	34 (31.5)	14 (13.5)	6 (6.2)
Feel ashamed if people knew a child in family has been diagnosed with autism			
Definitely not	55 (50.9)	88 (84.6)	87 (89.7)
Probably not	12 (11.1)	7 (6.7)	4 (4.1)
Probably	15 (13.9)	6 (5.8)	3 (3.1)
Definitely	26 (24.1)	3 (2.9)	3 (3.1)
Feel ashamed to be seen out on the street taking care of a child with autism			
Definitely not	62 (57.4)	96 (92.3)	94 (96.9)
Probably not	10 (9.3)	8 (7.7)	2 (2.1)
Probably	8 (7.4)	0 (0)	1 (1.0)
Definitely	28 (25.9)	0 (0)	0 (0)

Note: * denotes a reverse scored item in the social distance sum score

4.3.2.2. Mean scores and distributions of the positive beliefs, negative beliefs and social distance questionnaire score in each of the three groups

Figure 5, 6 and 7 show the mean scores and distributions of: the positive beliefs (Figure 5), negative beliefs (Figure 6) and social distance (Figure 7) scales in each of the three groups.

The total mean scores and SD of positive belief were 2.5±2.2, and the score for the HEAT trained, HEAT+ trained and untrained HEWs on positive belief were 2.6±2.1, 1.8±1.7 and 2.8±2.5 respectively. The total mean scores with (SD) for negative stereotype belief were 5.4±3.1, and the mean score with (SD) of group on negative stereotype were: (5.8±2.8, HEAT trained), (3.3±2.3, HEAT+ trained) and (7.0±3.0, untrained HEWs). The total means score on the social distance of autism questionnaire among the health extension workers were 4.2 ± 4.3. The mean score of social distance of autism questionnaire for the HEAT trained, HEAT+ trained and untrained HEWs group were 2.9 ± 2.8, 1.6±2.2 and 7.8 ± 4.4 respectively.

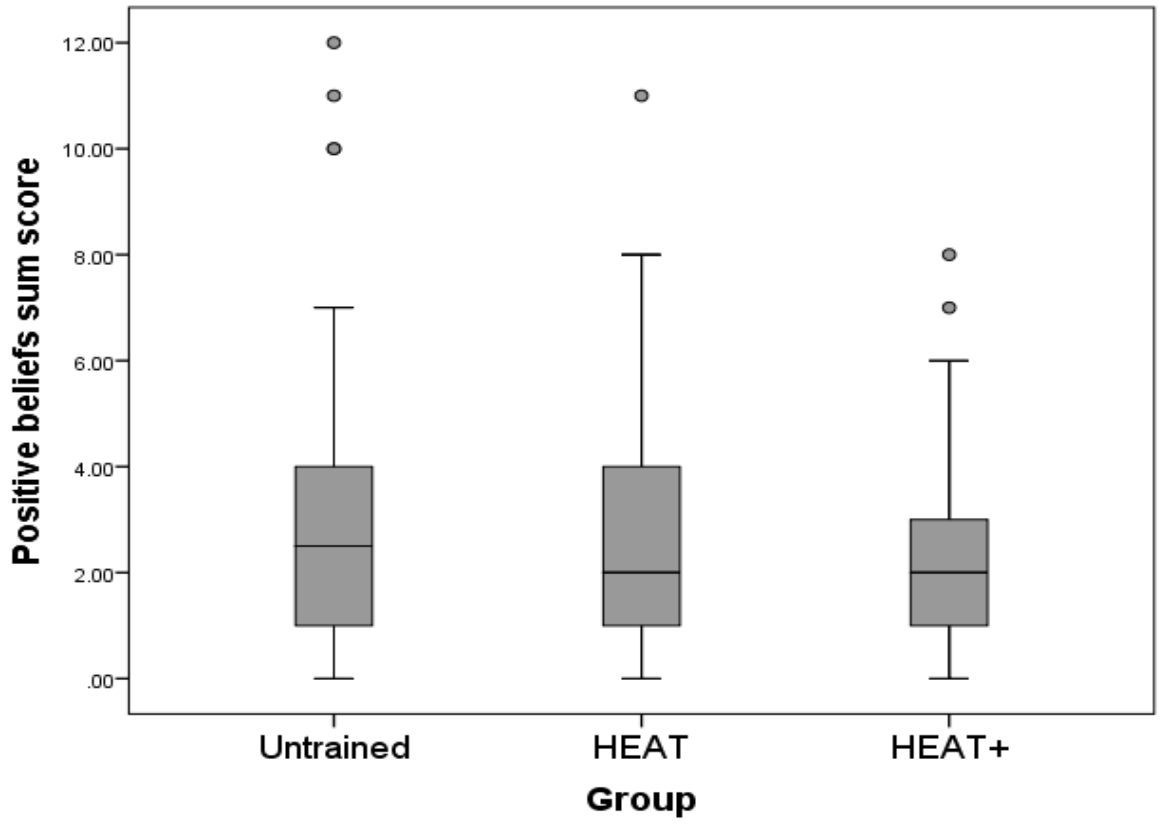


Figure 5: Positive belief towards children with autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

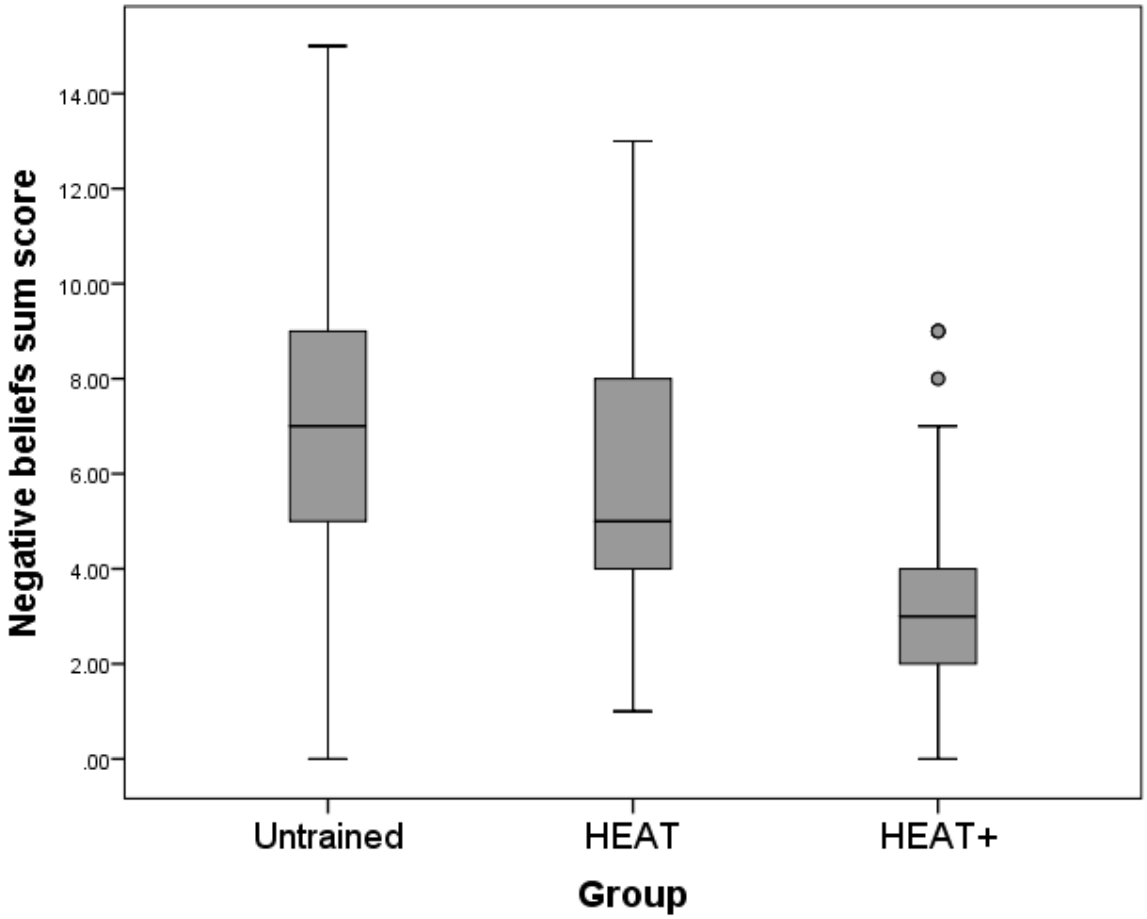


Figure 6: Negative beliefs towards children with autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

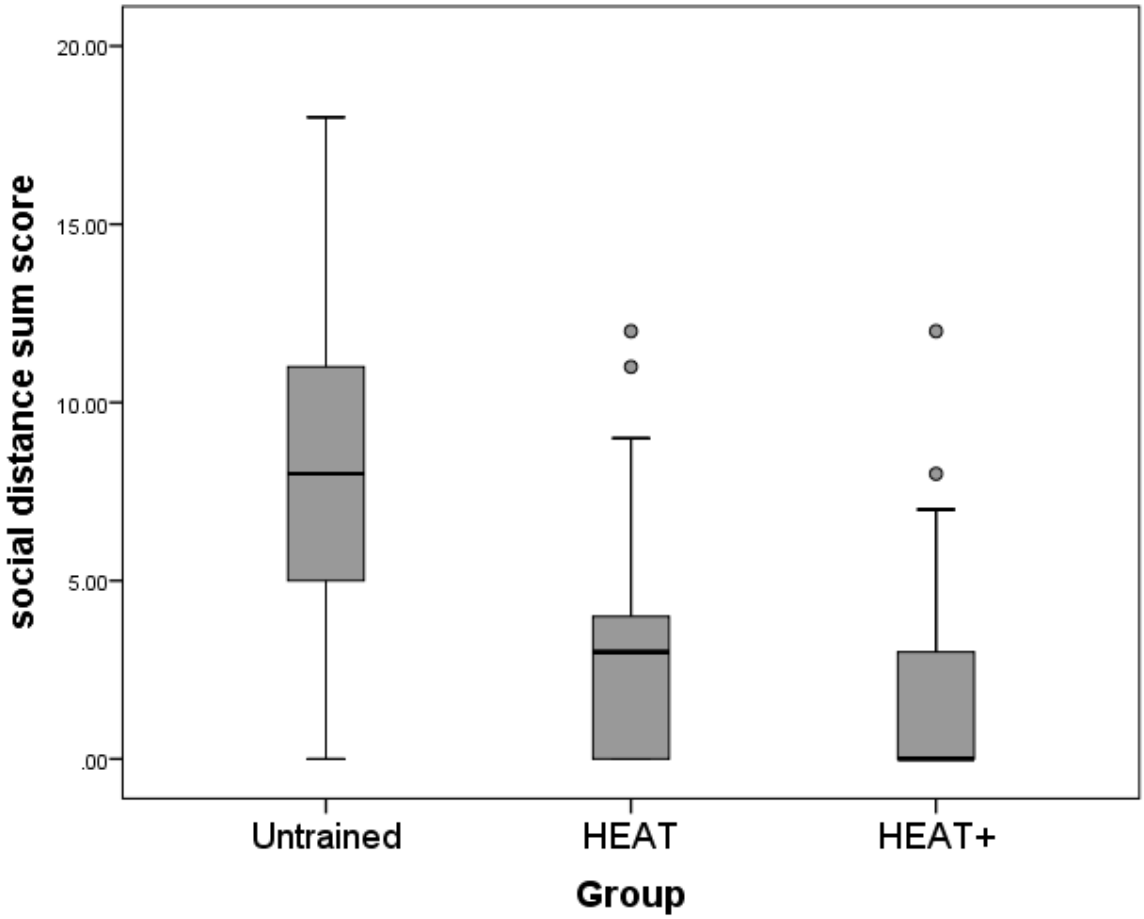


Figure 7: Social distance towards children with autism in HEAT trained, HEAT+ trained and untrained HEWs, SNNPR's, Ethiopia, 2013(n=309)

Note: a higher score on the positive beliefs (Figure 5) and negative beliefs (Figure 6) scales indicates stronger beliefs; a lower social distance score (Figure 7) indicates less desire to keep a distance from the child with autism suggesting decreased stigmatising attitudes

4.3.2.3. Impact of training on positive belief and effectiveness of language intervention, positive belief, negative and social distance toward children with autism

The groups differed significantly in their belief that a child with autism can improve their language skills with the right help (H (2) = 52.371, p< 0.001). Subsequent Mann-Whitney tests indicated that HEAT+ trained (Z=-6.24, p< 0.001, r=-.44) and basic HEAT trained (Z=-6.14, p< 0.001, r=-.42) HEWs were more likely to believe that children with autism can improve their language skills compared to untrained HEWs (Table 12). The HEAT and HEAT+ groups did not differ from each other (Z = -.46, p>.05)

Above Figure of sum score distrubtion shows the mean scores and distributions of the positive beliefs (Figure 5), negative beliefs (Figure 6) and social distance (Figure 7) scales in each of the three groups. There was a significant group effect on the positive beliefs scale (F (2, 301) = 4.57, p=.01, partial η^2 = .03). Planned contrasts using Bonferroni correction for multiple comparisons revealed that the HEAT+ group had significantly lower positive beliefs scores than the untrained group (p=.01); none of the other group comparisons were significant. None of the included covariates had a significant effect on positive beliefs (all p>.05). Significant group differences were observed for the negative beliefs scores (F (2, 301) = 45.91, p<.001, partial η^2 = .23). This comparison took into account the effect of whether the surveyed HEW had a co-worker trained in mental health (F (1, 301) = 4.08, p=.04, partial η^2 = .01). Both the HEAT (p=.004) and HEAT+ group (p<.001) showed fewer negative beliefs towards children with autism than the untrained group. The HEAT+ group in turn displayed fewer negative beliefs than the HEAT group (p<.001). Significant differences were also observed between the groups' social distance scores (F (2, 301) = 103.14, p<.001, partial η^2 = .41), taking into account the effect of having a trained or untrained HEW co-worker (F (1, 301) = 4.99, p=.03, partial η^2 = .02). Both the HEAT (p<.001) and the HEAT+ group (p<.001) showed decreased social distance towards children with autism compared to the untrained group; the HEAT+ group displayed a smaller preferred social distance than the HEAT group (p=.017).

Table 15: Summary of the findings by specific objectives, Ethiopia, 2012/2013

Specific objectives	Main finding
To determine the experience of stigma, explanatory models and coping strategy in caregivers of children with child mental health problems specific to developmental disorders (DD).	Most caregivers reported experience of stigma: 43.1% worried about being treated differently, 45.1% felt ashamed about their child's condition and 26.7% made an effort to keep their child's condition secret. Stigma did not depend on the type of developmental disorder, the child's age or gender, or on the age or level of education of the caregiver (all p>0.05). Reported stigma was significantly higher in caregivers who had sought traditional help (p=0.004), provided supernatural explanations for their child's condition (p=.018) and in caregivers of Orthodox Christian faith (p=.028). Caregivers gave a mixture of biomedical explanations (e.g. head injury (30.4%) or birth complications (25.5%)) and supernatural explanations (e.g. spirit possession (40.2%) or sinful act (27.5%)) for their child's condition. The biggest reported unmet need was educational provision for their child (74.5%), followed by treatment by a health professional (47.1%), financial support (30.4%) and expert help to support their child's development (27.5%). Most caregivers reported that talking to health professionals (86.3%) and family (85.3%) helped them to cope.
To assess training needs, expected role and perspectives of HEWs in relation to integrating child mental health care in to primary health care services	Most of participants (88.9%) were interested to study and learn about child mental health care. Most (96.3%) HEWs recognized the importance of the topic of child mental health problems. Nearly half, (47.2%) used reference materials at work place and the benefits reported after training were improved knowledge, motivation to do and read, identification of the case, counselling and referring cases. Only (36.1%) organized mental health awareness meeting. There is high training need on child mental health. The reasons for need of training were the widespread nature of the condition in the community and its huge burden to the family and individual. The need to improve their competency and performance, and reduce stigma and discrimination were other reason. Many barriers such as individual level barrier, community and health care system barriers were listed; additionally many facilitators as an opportunity were mentioned.
To evaluate the impact of training HEWs with the basic and enhanced HEAT program on childhood autism: Change in belief, attitudes and social distance.	The ten-items instrument used to evaluate impact of training had a 2-factor structure: one factor comprising four positive belief items, and one factor comprising five items assessing negative beliefs. Mann-Whitney tests indicated that HEAT+ trained (p< 0.001) and basic HEAT trained (p< 0.001) HEWs were more likely to believe that children with autism can improve their language skills compared to untrained HEWs. Planned contrasts using Bonferroni correction for multiple comparisons revealed that the HEAT+ group had significantly lower positive beliefs scores than the untrained group (p=0.01). Both the HEAT (p=0.004) and HEAT+ group (p<0.001) showed fewer negative beliefs towards children with autism than the untrained group. The HEAT+ group in turn displayed fewer negative beliefs than the HEAT group (p<0.001). Both the HEAT (p<0.001) and the HEAT+ group (p<0.001) showed decreased social distance towards children with autism compared to the untrained group; the HEAT+ group displayed a lower preferred social distance than the HEAT group (p=0.017).

5. Discussion

This study is the first in providing evidence on the impact of child mental health training for rural community HEWs in Ethiopia. Assessment among HEWs perspectives helped to identify gaps of skill, knowledge, attitude and suggested important area that needs to be inculcated in the enhancement of HEAT+ project. Specifically it was identified gaps of training needs on detection, treatment and prevention of child mental disorder including autism, and specific support in tackling negative attitude and social distance. Assessment among caregivers also identified the gaps in the service provision for thier children with DD and support to caregivers of children with DD and optimal way to address these gaps. Training using basic and enhanced HEAT materials have reduced respondents' negative stereotype and social distance and have also mixed effect on positive outcome toward children with autism in rural Ethiopia. The discussion of this PhD thesis includes base line and evaluation phase findings. The base line discussion of caregivers focuses on the stigma, explanatory model and unmet needs of caregivers with child DD; and basic HEAT trained HEWs discussion focuses on learning needs and experience, rationale for training barriers and facilitators in relation to integrating child mental health care in to community-based PHC services. The discussions on evaluation phase cover the findings that center on the impact of training of HEWs using enhanced HEAT mental health module and basic HEAT mental health module compared to untrained HEWs.

5.1. Stigma, explanatory models and unmet need of caregivers with child developmental disorder

This study indicates that stigma perceived and experienced by caregivers is common. Many caregivers worried about being treated differently, felt ashamed or embarrassed about their child's condition, and tried to explain their child's illness as different from mental illness or 'madness'. Other experiences, such as feeling depressed, or feeling that the problem is their fault are also common. This finding is consistent with research conducted in high-income countries that indicated the majority of caregivers felt stigma (15, 16, 18, 19, 47). Our study findings were also in accordance with other studies conducted in low- and middle-income countries, namely that caregivers of children with developmental disorders often experienced embarrassment, shame and guilt (20, 44, 46, 114). Although there are no such studies among caregivers of children with DD or ASD in Ethiopia, a study among caregivers of people with schizophrenia or major affective disorders using the FIS found similarly high levels of perceived stigma (114).

Investigators from India, Tanzania and China reported that the majority of caregivers of children with developmental disorders felt tired, depressed, exhausted and worried about their child's future role in society (20, 44, 50). However, these studies were purely qualitative and were unable to examine quantitatively which factors may be associated with stigma. Our findings suggest that caregivers seeking help from traditional institutions experience significantly higher levels of stigma than caregivers who did not seek this type of support. Moreover, Orthodox Christian religion and providing a supernatural explanation for the child's problems were predictive of high reported stigma. These are important clues regarding what the focus of intervention may in part need to be. However, as this is a cross-sectional study, it was not possible to examine the direction of causation of the association between traditional support and perceived stigma. That is, it remains unclear whether engaging with traditional institutions may increase experienced stigma, or whether families who experience high levels of stigma are more inclined to seek support from traditional institutions.

In this study, caregivers cited a mix of biomedical and supernatural factors as causes for their child's condition. Many caregivers reported that they perceived both supernatural factors, such as spirit possession, the result of a sinful act or punishment from God, and biomedical factors, such as a head injury, birth complications, or epilepsy to be the cause of their child's developmental disorder. This result is consistent with studies in Taiwanese parents (47) and Indian parents living abroad (49), who also reported a mix of biomedical and supernatural causes of their child's condition**.** Similarly, in a previous study from Ethiopia, where the explanatory models of parents of in-school children for child mental disorders were investigated, the majority endorsed both biomedical and supernatural courses (52). These results suggest that supernatural and biomedical belief systems often co-exist. It should be noted that, given that all study participants were recruited from a specialist referral hospital, selection bias may have led to a higher proportion of participants from our study endorsing biomedical causes than may be observed in the general Ethiopian population.

Most respondents (92.2%) in this study believed the child's condition to be curable. This finding suggests caregivers may have somewhat unrealistic expectations of what can be achieved with interventions or treatment, perhaps suggesting a risk for dissatisfaction among caregivers with

the outcome for future interventions. However, 'social desirability' bias may also have played a role: since the study was conducted in a mental health clinic and the data collectors were psychiatric nurses, caregivers may have been inclined to over emphasise their belief in a (biomedical) cure. A further explanation for the strong confidence in curability could be religious beliefs. A study carried out among South Asian Muslim immigrant families reported that families understood the task of raising a child with autism in religious terms (115). In that study, parents reported that keeping to the precepts of Islam would help them to raise their developmentally disabled children as normally as possible. The high level of belief in curability in our study may similarly be explained by the fact that Ethiopia is a deeply religious society and not believing in a cure could be understood as questioning the power of God. In a Kenya study, parents of children with ASD reported that they hoped for a cure and sought treatment with this expectation in mind (51).

The majority (67.6%) of the participants in this study indicated that they believed their child's developmental disorder to be very or quite severe. In the Ethiopian context, where access to child mental health services is extremely limited, only the more severe cases will reach the clinic. Therefore, our sample is likely to include more severe cases of developmental disorders than the full ID and ASD spectrum that may attend clinics in better resourced countries. As there are no validated tests of intellectual ability for use in Ethiopia it was impossible to provide a quantitative description of the extent of childrens' developmental disability.

Many caregivers indicated they used a combination of traditional and biomedical interventions to help their child. This is comparable to studies done in high-income countries (19, 47) that reported caregivers used multiple services and treatment strategies to help their developmentally disabled child including psychological, medical and paramedical services (19), as well as special diets and traditional treatments (19, 47, 49). For example, in Taiwan parents reported engaging in spiritual rituals such as paying a monk to read the Buddhist Bible and changing the name of the child to change his "fate". Similarly, our study found rituals related to the prevalent religions in Ethiopia (Orthodox and protestant Christianity and Islam) and traditional belief systems to be common. The wide range of interventions tried by caregivers may reflect the fact ASD and ID are lifelong conditions, so caregivers keep looking for answers and treatments.

A significant minority of caregivers indicated they have beaten (18.6%) or chained (8.8%) their child to manage their child's problems. These findings indicate that psycho-education initiatives are needed to prevent child abuse. Beating a child in an attempt to teach them to improve their behaviour is still common in Ethiopia. However, in a study in which we interviewed service providers for children with autism (45), it was highlighted that chaining is usually done not as a punishment, but to protect the child from harming themselves or others when there is no-one to look after the child.

The majority of caregivers (74.5%) indicated an unmet need for appropriate educational provision for their child, followed by treatment by a health professional (47.1%). In addition, many caregivers expressed they needed financial support (30.4%), access to professionals to help support their child's behaviour and skills development (27.5%) and access to expert information and advice about their child's condition (22.5%). These perceived needs of caregivers in our study are comparable to studies from high-income countries (19, 21), in which the majority expressed a need for educational services, health service provision, support for social activities, and access to information. A systematic review of studies conducted in Brazil indicated a similar set of unmet needs (116). Likewise, a study conducted in Tanzania (20) indicated that caregivers expressed a desire for support with schooling, professional assistance, health education and information, and social supports. This common set of unmet needs reported by caregivers among different studies is likely to be because of the similarity of the behaviours or needs of children with ASD or ID regardless of the setting they live in. However, the service provision for children with developmental disorder in high-income countries is rather different from the provision available in most low- and middle-income countries. Even though the provision may be perceived as inadequate most children in high-income countries will get some type of support and special education (although stark differences may exist between socioeconomic groups). In contrast, in Ethiopia most children with developmental disorders do not get any provision; most remain undiagnosed and specialist schooling and intervention is unavailable in rural areas, where 85% of the population lives (45). Although the service provision for children with developmental disorders in low- and middle-income countries is not well-documented, the challenges reported in Ethiopia are likely to also apply to other low resource countries and settings.

The most common coping mechanisms used by caregivers in our study were talking to health professionals, talking with family or friends and prayer. This result is consistent with a systematic review of coping strategies of families affected by autism in Brazil, where caregivers were assisted by access to medical care, information exchange between families and seeking religious support (116). Talking to family and friends was another important coping mechanism reported frequently by parents from the Philippines (117) and in studies conducted in high-income countries (21, 49, 118). Our study indicated more than half (57.8%) of the respondents reported prayer as a coping mechanism, reflecting the importance of religious faith within society. This finding also highlights that, while seeking help from traditional institutions was related to higher experienced stigma, many caregivers find support in their religious beliefs and rituals through prayer. In a study from the Philippines, religion and spiritual practices seemed to provide positive social support for parents of developmentally disabled children; church members offered emotional support, guidance, frequent company and acceptance of their children (117). In a study from rural Ethiopia in relatives of people with schizophrenia many relatives were also inclined towards prayer for guidance and talking with someone about their problems as a coping mechanism (22). Similar to our findings, the study participants valued their contact with health professionals in enabling them to cope. This might reflect the high status of health professionals in Ethiopia and indicates an important role of the health sector in supporting caregivers of children with child developmental disorders.

In the majority of cases (52.9%), the family found their way to the clinic through referral by a health extension worker. Health extension workers provide basic health services in the local community. Since 2003 the Ethiopian government has trained 39,000 of these community health workers, with two health extension workers deployed in each community (ward). Our study suggests that these workers play an important role in identifying developmental disorders and thus form a gateway to specialised help.

5.2. Training needs and perspectives of health extension workers in relation to integrating child mental health care

In addition to assessment of perceived stigma, explanatory model, coping mechanism and unmet needs of caregivers of child with DD, this initial study also assessed the training needs and perspectives of HEWs in relation to integrating child mental health care in to primary health

service to identify the gaps and then helped to inform for the enhancement of HEAT program. We also assessed barriers and opportunity for integration of child mental health care performance in to community-based primary health service. Therefore, the next section discussed on findings of training needs and and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care into community-based PHC services in Ethiopia.

The burden of mental disorders among children in the community was considered high. We found a high level of interest and motivation to learn about mental health needs of children and to provide services and HEWs had positive attitude towards the HEAT training resources. HEWs believed that, through the training, they would be able to improve quality of care and address the issue of the widespread stigma and discrimination of mental health. Integration of mental healthcare of children into routine community based primary care practice was acceptable to the HEWs. In addition, several facilitators and barriers for integrating child mental health care were mentioned by HEWs.

The positive attitudes of HEWs towards training about mental health needs of children and the HEAT study resources may facilitate the implementation and integration of mental healthcare of children into primary healthcare. This is consistent with previous findings in LMICs among CHWs that indicated good acceptability of training and the role of motivation in the implementation of services at primary healthcare level (70, 119) and the positive impact of training on improving knowledge, skills, satisfaction and motivation and actual performance (74). Other studies in LMICs also showed an increase in confidence, motivation and service performance at the work place after training of CHWs (70, 73, 75, 120-122).

One of the encouraging findings of this study is the fact that even though most HEWs had only recently returned to their community to work as HEW after completing their upgrading training, nearly half of the trained HEWs have been using the mental health training materials regularly in their practice. This has resulted in reported improvements in knowledge, skills and attitudes consistent with reports of improved knowledge, competence and performance among HEWs with the use of guidelines and protocols (70, 120-122). Interventions to encourage the consistent

use of the training materials or improving their utility either developing simpler pocket guides or flow charts may be an important next step.

A third (36.1%) of the participants had organized a mental health awareness-raising meeting within four months of training. Given the short time following training to organize mental health awareness meetings and the competing responsibilities HEWs have, organizing these meetings appear to be an important achievement induced by the training.

HEWs consider mental health needs among children to be common and this was their primary justification for perceiving that they needed training. They believed that training of frontline HEWs was important in addressing the treatment gap in children. Such rationales have also been identified elsewhere (123, 124) and speak to the need to include public health arguments about the population level benefits of community interventions. The related issues of family needs were also considered to be important reasons for the training. Childhood health needs are reflections of the broader family need and may impact seriously on the broader family context. Again this is also an important consideration in developing training resources for community providers who interact with families as part of their routine practice.
The need for improving knowledge and confidence in case detection, and quality care provision were mentioned as important rationales for training, which were consistent with other reports from Ethiopia (39, 78, 79, 125) and elsewhere (70, 126).

In our study, poor knowledge and skill were the frequently endorsed barriers for integration of child mental health care into primary care. The majority of the study participants reported that they did not know how to detect, support and prevent mental health problems as a result of poor competency. This finding is consistent with other reports among HEWs (78, 79) in Ethiopia and CHWs (70, 72) in LMICs. The other barriers were negative attitudes and stigma (81, 82). Compared to other aspects of their work, the high challenge of child mental health care for HEWs in our study may be related to the low baseline knowledge and the lack of referral services and stigma. Moreover, the broader lack of research and policy guidance may play a part. For example child mental disorders were not included in the implementation of the mental health gap action programme in Ethiopia or other implementation studies, such as the Programme for

Improving Mental Healthcare (81, 127). It is important to develop research evidence such as presented here to support the scale up of mental healthcare and also address negative attitudes and stigma among HEWs and families (73, 75).

The other barriers mentioned in our study were demotivation as a result of low expectation of the community and other stakeholders from the HEWs. Similarly, unrealistic expectations, for example, the vast majority expecting cure (82), poor planning and underestimation of the effort required, were causes of numerous failures of programmes and damaged the credibility of providers (75, 128).

Institutional level factors, including lack of availability and accessibility of services and facilities, and lack of resources such as time, trained health professionals, and lack of supervision and coordination were also reported to be barriers for integration of the service, in keeping with findings from programmes for other disorders (70, 79, 119, 128).

The recognition of child mental health problems as important and the overall positive rating of the training materials may facilitate integration of child mental health care into routine primary care. Such factors are identified as important enablers of integration and sustainability of programmes implemented by CHWs (70, 74, 119). The use of the reference resources provided by the training programme and engagement in organization of community awareness programmes are potential enablers, as were identified elsewhere (70, 89, 119, 122, 129). However, nearly a fifth of the trainees did not have access to the training materials and this problem was augmented by the language difficulty. This speaks for the need for careful adaptation and piloting of such resources before they become more widely available.

The HEWs believed that their training had improved their knowledge, skill and confidence to detect mental disorders in children and to help family members of children with developmental disorders. This confidence, coupled with the high motivation and willingness of HEWs to apply their training, would be important facilitators of integration into routine practice (89, 119). The new role of supporting child mental healthcare is also consistent with the role HEWs felt they had and this perception would also be an important facilitator (70, 124, 130).

The evaluation of the impact of the HEAT/HEAT+ training resources suggest that the HEAT mental health training, particularly the HEAT+ (enhanced) training, improved the CHWs' negative stereotype and social distance relation to autism. It has also mixed effect on positive outcome belief toward autism. And these impacts at evaluation phase were discussed as below.

5.3. Impact of training health extension workers on belief, attitude and social distance

This impact evaluation study is also the first study in Ethiopia, and to our knowledge in Africa, that provides evidence on the impact of both basic and enhanced educational interventions on the beliefs and attitudes of community health workers towards children with autism. We find that both educational approaches have a significant impact in improving attitudes and negative beliefs, with more mixed findings regarding positive beliefs about children with autism.

Compared to untrained HEWs, both the HEAT+ and the HEAT trained groups of HEWs were more likely to think that children with autism can improve their language skills with the right help. While two third of the HEWs not yet trained in mental health and developmental disorders thought children with autism will never or rarely improve their language, only a minority of HEAT (23%) and HEAT+ (16%) trained HEWs had such low expectations of the efficacy of a language intervention. Against expectation, HEAT+ trained HEWs were less likely to have positive beliefs about children with autism, e.g. that they can make their parents proud, can attend school, can get married when they grow up, and can play normally with other children. This unexpected finding may perhaps be explained by the exposure of HEWs in rural Ethiopia to predominantly severe cases of autism. Identified children with autism in Ethiopia nearly always have comorbid intellectual disability (82). The limited positive beliefs of HEAT+ trained HEWs' may also reflect their improved knowledge about autism (compared to the other two groups who received little or no autism-specific training). The practical reality is that severely affected children are unlikely to get married later, and unlikely to fit in mainstream education, in the absence of specialised autism education (81). Our finding of no difference between the HEAT and untrained group is consistent with a number of previous mental health education studies that observed no significant change in positive attitudes or beliefs in a positive outcome for mental health patients in community health workers (73, 131) and occupational health students (132) after training.

Compared to HEWs untrained in mental health, both HEAT and HEAT+ trained HEWs were less likely to endorse negative beliefs relating to children with autism. The HEAT+ trained group in turn endorsed fewer negative beliefs than the HEAT trained group. Importantly, HEAT or HEAT+ trained HEWs were unlikely to believe that children with autism 'need to be chained up at home', while 18% of untrained HEWs thought this would 'often' or 'nearly always' be needed. Chaining and beating children with DD is still common in Ethiopia (82). It is thus encouraging to see that a brief training appears to reduce the belief in this practice. The effectiveness of the HEAT and HEAT+ programme to change negative beliefs is in keeping with previous mental health education intervention studies in health workers (75, 86, 133, 134), occupational health students (132), police officers (91) and young people (99). One explanation of the greater impact of HEAT+ compared to basic HEAT may be the use of videos in the former. Previous mental health intervention education studies suggest that video-based education is more effective in changing attitudes than lecture-only education (100, 135). An alternative explanation may be that the effect of basic HEAT training is reduced in this study as the training was provided sixteen months prior to data collection (in contrast to the HEAT+, which was provided four months prior). Previous studies suggest that positive effects of mental health training may decline over time (99, 136).

Both the HEAT and the HEAT+ group showed reduced preferred social distance towards children with autism compared to the untrained group, suggesting decreased stigmatising attitudes. The HEAT+ group displayed a lower preferred social distance than the HEAT group. Fifty percent of the HEAT+ HEWs obtained a score of zero on the social distance scale, suggesting they have no need for social distance towards children with autism. The effect of the intervention is in keeping with previous reports that examined changes in the social distance towards people with mental health problems in community health workers (75, 133), police officers (90) and young people (99). The results are also consistent with previous reports that video-based training is more effective in reducing social distance than lecture-only methods (100, 135)

6. Validity, generalizability and implications

6.1. Validity and generalizability

Validity refers to conceptual and scientific soundness of research study or investigation. Validity takes different forms including content, criterion-related and constructs validity (137, 138).

Content validity refers to whether the items measure the substance or subject matter they were intended to measure. In this study, content validity was achieved in two ways. The first one was through administering the instrument in Amharic, the language that was familiar and well understood by all the data collectors, HEWs and caregivers who participated in the study. The translation of English version questionnaire in to Amharic, then back translated in to English and pretesting the Amharic version prior to final data collection were important steps taken to ensure content validity. *Second*, as mentioned earlier, the pre test was carried out in similar setting prior to the main study conducted at the child mental health clinic at Yekatit 12 Hospital and at Butajera, region in the Southern Nations, Nationalities, and People's Region (SNNPR) so as to test the content of the instruments for data collection.

The study also has to determine the criterion-related or predictive validity, which reflects whether the finding corroborate results of previous studies. One way to obtain this would be to use standardized questions that provide a criterion measures. However, due to the lack of training effect related to child developmental disorder (autism) interms of impact and change in belief, attitude and social distance scales that had been tested to check internal consistency or test-retest reliability in previous studies conducted elsewhere, it was implausible to establish criterion-related validity.

Generally, making possible efforts to increase the internal and external validity of the findings is a mandatory procedure in any study. In this regard, this dissertation tried to utilize possible options to increase both the internal and external validity at all stages, including during design, data collection processes and data analysis.

6.1.1. Internal Validity

Internal validity refers to absence of systematic error that causes the study findings to differ from the true values as defined in the study objectives (139). While the results of a study may reflect

the true effect of an intervention (training) on the development of the outcome under investigation; it should always be considered that the findings may in fact be due to an alternative explanation. Such alternative explanations may be due to the effects of chance (random error), bias or confounding, which may produce spurious results, leading to the conclusion of the existence of a valid statistical association when one does not exist, or alternatively, the absence of an association when one is truly present (139). Thus, this study tried to consider in addressing the role of chance, bias and confounding.

The role of chance in this study was addressed by using adequate and representative sample sizes which were estimated based on power in our study. In addition, the largest sample size was used for all the objectives to increase precision and power. Bias may arise as a result of selection bias or information bias (139). In this dissertation selection bias has minimal effect due to random selection and sampling of HEWs via regional health office. Moreover, information bias also had minimal effect in this study because of different measures taken during the study. For example, in order to reduce the information bias due to data collectors, similar data collectors, females who completed 10th grade, familiar with the local languages and culture were used at the baseline phase as well as at evaluation phase. The instruments were also adapted from standard questionnaires and pre-tested before actual data collection. Intensive training and supervision were also done for better understanding of the instruments and accurate recording. Incomplete and inconsistent questionnaires were also recompleted. Local languages were used to reduce misunderstanding by the respondents. To address confounding, this dissertation tried to identify as much factors as possible from the existing literatures and developed conceptual framework during designing stage. Multivariate analyses were also done to control for the possible confounding factors.

6.1.2. External validity (Generalizability)

External validity is the extent to which the results of a study can be generalized to other situations and to other people at other places and at other times. In this study generalizability was ensured through random sampling, triangulation of methods and data sources, (for e.g. by asking similar questions to different group of HEWs (trained or educated with HEAT program, trained with enhanced HEAT program and untrained HEWs). Moreover, to ensure the validity and

reliability of study, we were also applied various actions, starting from questioner designing to supervision, were instated to assure its quality. The tool was pretested and its reliability and content and construct validity had been properly assessed. Data were gathered using qualified, experienced and appropriately trained personnel. During data collection strict supervision was made by principal investigator and trained supervisors. The acceptable psychometric properties of the scales assessing positive and negative beliefs and social distance following adaptation of existing scales could also increase validity of the findings.

Generally, in this study we implemented a range of mechanisms to ensure the study's internal and external validity, potential biases that would affect the study's validity were considered and addressed from the outset. Additionally, based on the conceptual framework, the study has had gathered information on a wide range of pertinent variables and potential confounders were statistically controlled. Then depending on the base line information learning materials were developed both in English and Amharic language. Then implementation of the developed intervention was done; finally evaluation of the intervention to see the effectiveness of the program was conducted. Furthermore, this study focused on a setting where no or very little similar studies were conducted. Consequently, the findings of this study might not only fill the research gap of the country but also help policy makers and implementers of child developmental disorder including autism, care, treatment, preventions and support program in the country.

6.2. Implications

Implications for practice

This research has a number of implications for professionals working with caregivers and children with developmental disorders in Ethiopia and other low resource settings. First, in response to the high levels of perceived stigma in caregivers, there is a need to design interventions to improve public awareness about developmental disorders, decrease stigma and improve access to appropriate services. Second, although causality cannot be inferred, in response to the finding that stigma experience was significantly stronger in caregivers who had sought help from traditional institutions, there is a need to work collaboratively with traditional and faith healers, for example, by organising joint public awareness and anti-stigma efforts with these traditional institutions (140). We do not advocate discouraging seeking help from traditional and religious institutions, as many caregivers feel supported by these systems; it is

also illustrated by the high percentage of caregivers indicating they used prayer as a coping strategy. Third, we also found that many parents hold both supernatural and biomedical causal beliefs and that the two aetiologies are not mutually exclusive, with most participants giving both biomedical and supernatural explanations. Based on this finding, it is necessary to train healthcare providers to be empathetic to the needs and conditions of caregivers and be open to the possibility of collaborative engagement with traditional healers for the holistic care of children with developmental disorders (140). Health professionals need to respect caregivers' beliefs and supernatural explanations, while also sensitively providing psycho- education on causes and helpful strategies to support their child, and discourage harmful practices such as beating and chaining. Fourth, the finding that caregivers' coping mechanisms include talking to health professionals, family and friends as a main mechanism to cope the problems can help professionals to prepare different strategies in counselling and the delivery of psychosocial interventions. In low-resource settings such as Ethiopia, community-based psychosocial interventions delivered by non-specialists (e.g. community health workers, primary care workers or peers), are a viable strategy to scale-up support for families with children with developmental disorders(5).Since most parents believe their child can be cured, this expectation of a cure needs to be born in mind when designing a psychosocial intervention. Fifth, the finding that health extension workers form the main gateway to access to biomedical services highlights the importance of increasing awareness of developmental disorders among health extension workers to increase identification of ASD and ID in the local community.

Similar to caregivers of children with DD findings, the base line study of HEAT trained HEWs have also many implications for health care professionals and stalkholders at community and primary level of health care service. The enthusiasm of HEWs on the training, recognition of training about DD and ASD, interest and participation in actual service provision of child mental health care implies the feasibility of the program for scale up and integration in to primary health care service. Thus it is great opportunity for the policy makers and concerned bodies to promote integration of child mental health care in to PHC service.

The finding of the unmet needs of training of HEWs in terms of knowledge and skill or competency highlight the need for in-service-training of HEWs on child DD including autism.

A wide spread negative stereotype belief, social distance and stigma and discrimination of the child with DD and parents of child with DD among untrained HEWs implies for an urgent need of developing more effective awareness-raising, training and education programme among HEWs and calls for in-service training.

The training need and perspectives of HEAT trained HEWs on training and/ integration of service in to PHC provides valuable lessons; firstly, it suggests that the curriculum of child mental health related to child DD needs to be modified in terms of approaches of teaching, and area of contents that would be included. Secondly, it helped to enhance and develop materials appropriate to HEWs. Thirdly, it provides valuable lessons for countries that established CHEW models and intend to provide rigorous training as one of the key program elements.

The different barriers, from qualitative findings, such as poor competency and stigma of HEWs and general health worker, and health system constraints such as lack of services, facilities may hinder the scale up of training and integration of child mental health care. Hence, before implementation of the program to a large population, it is essential to find appropriate strategy for addressing barriers. So, if child mental health care is going to be integrated successfully into community level; individual barriers and health services problems will need to be solved and FMOH also need to give attention for availability of service and facilities.

It was encouraging that a brief training had a recognizable impact on reducing negative beliefs and social distance. Community health workers could play important roles in decreasing stigma in the community and in community rehabilitation for children with developmental disorders. Decreased negative beliefs amongst HEWs may contribute to decreased stigma and negative beliefs in the community as a whole; decreased social distance from HEWs to families with a child with autism is likely to facilitate community rehabilitation, for example through the use of non-specialist workers to administer psychosocial interventions in the community (5). The mixed effects of the HEAT+ training on positive beliefs about children with autism highlights the need for carefully designed educational interventions, taking into account the local practical and sociocultural context. The finding of a stronger effect of HEAT+ compared to HEAT training (with the caveat of the greater time lag in the HEAT group) echoes the emerging finding in mental health education research that different forms of training do not all create the same

effect, and video presentations may be an especially powerful training method to reduce stigma, especially in training situations where direct social contact is not feasible (100, 135).

The HEAT and HEAT+ study materials are open educational resources that are free to be adapted and used elsewhere. Given that similar challenges related to autism and mental health are reported elsewhere, the lessons learned in this study are likely to have relevance for training community health workers in other low-resource settings. A recent review highlighted the lack of evidence for interventions to reduce mental health-related stigma conducted in LMIC (141). Our findings are thus likely to be relevant to addressing stigma relating to a broader range of mental health and developmental conditions too.

Implication for policy

The Ethiopian health care system can integrate evidence from this study to include child mental healthcare into its broader care integration plans. Although it is assumed here that this integration would have important economic returns for the country, careful economic evaluation of integration is needed.

Implications for Research

There is a need to investigate the effectiveness of educational interventions using RCTs and longitudinal designs. Interventions which can produce lasting impact in positive attitude change need to be developed.

7. Strength and limitation

7.1. Strength

Several strengths distinguish the current study. The strengths pertain to: (1) the multiple and complementary studies that were conducted; (2) the attempts to develop instruments carefully; (3) the development of a training intervention although as part of a bigger study; (4) evaluation of the impact of the training intervention in a simple less costly approach; and (5) the potential policy implications of the findings and the applicability of the findings to other similar countries and settings. Additionally, the study is the first study in Ethiopia among the caregivers of children with ASD or ID and HEWs, and provides information in an area of public health of which very little is known, not just in Ethiopia, but in sub-Saharan Africa more widely. Moreover, the high participation of participants and high consistency with other studies in caregivers of children with developmental disorders supports the reliability of our findings.

Moreover, the study was conducted across a predominantly rural area and included a sample of HEWs, ranging from relatively inaccessible facilities to those located near to the regional and zonal town. The other strengths of the study are that it was an intervention study addressing key evidence gaps. Despite the moderate sample, the effect was sufficiently large to obtain a statistically significant increase in attitude and social distance.

7.2. Limitations

This study suffers from the following limitations: The caregiver study included respondents, who lived primarily in urban areas; the findings may not be generalisable to more rural settings in Ethiopia. This caregiver study was also facility-based, and thus was biased towards those with higher educational level and ability to access biomedical care. The experiences of these caregivers may differ from families whose child with similar problems has not (yet) been diagnosed. We were not able to determine how long ago the caregivers were first informed of their child's diagnosis, nor since how long the caregivers had been concerned about their child's development. The perspectives of caregivers who have long been aware of their child's condition may be different from those who have only recently become aware their child's development is atypical. Also, our sample of caregivers of a child with ASD was small, providing limited power to compare the stigma associated with that of ID only. Additionally, the cross-sectional study

design restricts our ability to draw causal or temporal associations. Since the study was conducted by psychiatric nurses and touches on potentially sensitive issues, the possibility that respondents reported information based on their perception of what the interviewer wanted to hear (i.e. a 'social desirability' bias) cannot be excluded. In addition, it must be noted that the finding of this study represent only caregivers and HEWs perceptions. We did not study the reflection of community and other stakeholders.

In relation to the study of the perspectives and of needs HEWs, the following limitations are noteworthy. First, the findings represented only the perceptions of HEWs. We did not study the reflections of children with developmental disorders or their families and other stakeholders. Second, the HEW program is relatively new to the Ethiopian health care delivery system, which limits the comparisons of the current findings with similar studies conducted earlier. Third, although the addition of the qualitative study enhances the relevance of our findings, the study only included HEWs from SNNPR; views expressed by our participants may not reflect views of HEWs working in other regions. However, stigma and misconceptions about autism are widespread in sub-Saharan Africa (32, 51, 142), suggesting that our findings may apply more widely across Ethiopia and be relevant to settings elsewhere in Africa.

In evaluating the impact of the training intervention, limitations relate to social desirability bias, matching and self-reported nature of the responses. First, although we tried to limit social desirability bias by employing independent data collectors of similar socio-economic status to the participants, it is conceivable that socially desirable responding may have played a role. Against this interpretation, the HEWs who took part in our initial evaluation of HEAT (85) appeared open to share their opinion on what they did not like about the programme (for example, dissatisfaction that the original HEAT materials were only available in English, rather than Amharic). A second limitation is that our groups were not perfectly matched: The HEAT group was significantly older and had longer work experience as HEWs compared to the other two groups, and the untrained group had a slightly higher mark in high school compared to the HEAT group. Moreover, the time lag in between the survey and the HEAT and HEAT+ training was different: the HEAT group had completed their training sixteen months prior, while the HEAT+ group had completed their training only four months prior. Differences between the

HEAT and HEAT+ group may thus also be explained by this time lag difference. Third, the enhanced HEAT materials included both a DVD and a mental health pocket guide. From our current study we cannot deduce whether it was the exposure to video materials or access to the pocket guide or both that generated the impact in the HEAT+ group. A final limitation is that this study did not consider whether the training had a direct impact on children with autism and their families. Our study is limited to self-reported beliefs and attitudes; future studies are warranted to examine whether these self-reported changes in beliefs and attitudes translate into tangible differences for families with children with autism

8. Conclusion

Caregivers of children with ASD or ID in Ethiopia face many challenges, including high levels of stigma and a lack of appropriate provision for their child. The study confirms the diverse stigma perceived by caregivers and to some extent confirmed by providers. The study also indicates that mental healthcare for children could be integrated into the existing plans to scale up mental health and the broader health service provision. Interventions to improve awareness about developmental disorders, to decrease stigma, and improve access to appropriate education and support for caregivers are warranted.

If the key barriers to service provision are addressed and supported by policy guidance, HEWs may contribute substantially in addressing the treatment gap for children with mental health needs.

Although, the current training intervention has clear impact in reducing negative attitudes and beliefs, future research needs to investigate how beliefs in a positive outcome can be preserved while developing an increasing awareness about autism in a challenging low-resource setting.

9. Recommendations

In the light of the above findings and conclusions, the following recommendations are made.

For policy makers and program designers

- A need to design appropriate policies and strategy to guide healthcare delivery to children with mental health problems including autism.
- A need to design appropriate interventions to improve awareness about developmental disorders to reduce stigma, and improve access to appropriate education including special school service and support for caregivers so as to improve quality of life of child and caregivers/family.
- Preparing concrete strategies on how to give in-service and continuous training for all HEWs and health care professionals depending on major gaps and challenges outlined in the study.
- Stigma and discrimination related to child mental disorder including DD and autism should be given due attention and behavioural change targeted communication should be designed and implemented towards child mental disorders and autism.
- Support to caregivers and individual should be initiated, advocated and strengthened starting from household level to the public at large and organizations working on child mental disorder and autism support should be encouraged and the whole community should be taught thoroughly to support of child with mental disorders including autism.

For ministry of health including regional health office, training colleges and Ministry of education and stalkholders

- Expanding the HEAT+ training (face to face class room teaching with video and pocket guide) to increase the impact in terms of awareness raising and stigma reduction.
- The ministry of health and its collaborators in child mental health care including autism and support program should allocate more resources to improve the quality of service and to be able to reach the society at large.
- A need of ongoing/continuous and in-service training for professional development and knowledge advancement for improvement of practical learning.
- Ensuring availability and accessibility of culturally sensitive reference materials (video and short hand book translated to Amharic) for all HEWs.

- Given that mental health including child DD and autism is significantly a stigmatized health problem due to its chronic characters, it is very important to design awareness related messages that would mitigate subjective feelings of child DD related stigma for HEWs, care givers, community and students at primary, secondary and tertiary level, so as to increase service seeking for individual and family and caregivers of a child with developmental disability.
- Various conference forums and the effective use of media to promote evidence based practice and the minimizing of myths about child DD including autism held by the general population and in particular among the healthcare professionals is much needed in Ethiopia.
- Scale up through task share/task shift, and integrating tasks with other different collaborators and sectors also need more attention.

Future research

- Since the present study is just an initial step towards exploring caregivers and HEWs unmet need and challenge and the effects of training HEWs related to child mental disorder, there is a need for large scale or nationwide studies to consolidate much needed empirical evidence on effect among caregivers, rural community HEWs and other primary health care professionals.
- Future research also needs to investigate how it can be assured that positive outcome belief changes prevail over time about autism in a challenging low-resource setting.

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12. Appendices

Annex 1: Published articles and manuscripts

Annex 1.1. Tilahun D, Hanlon C, Fekadu A, Tekola B, Baheretibeb Y, Hoekstra RA. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. BMC Health Services Research 2016, 16:152. DOI 10.1186/s12913-016-1383-9 (**published**).

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RESEARCH ARTICLE Open Access

Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey

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Abstract

Background: Understanding the perspectives of caregivers of children with developmental disorders living in low-income countries is important to inform intervention programmes. The purpose of this study was to examine the stigma experiences, explanatory models, unmet needs, preferred interventions and coping mechanisms of caregivers of children with developmental disorders in Ethiopia.

Methods: Participants comprised caregivers ($n = 102$) of children with developmental disorders attending two child mental health clinics in Addis Ababa. The majority (66.7 %; $n = 68$) had a diagnosis of intellectual disability (ID); 34 children (33.3 %) had autism spectrum disorder (ASD) as their primary diagnosis. All caregivers were administered a structured questionnaire via a face-to-face interview, which included an adaptation of the Family Interview Schedule, closed questions about socio-demographic characteristics, explanatory models of illness, type of interventions used or desired and coping strategies, and an open ended question regarding the family's unmet needs.

Results: Most caregivers reported experience of stigma: 43.1 % worried about being treated differently, 45.1 % felt ashamed about their child's condition and 26.7 % made an effort to keep their child's condition secret. Stigma did not depend on the type of developmental disorder, the child's age or gender, or on the age or level of education of the caregiver (all $p > 0.05$). Reported stigma was significantly higher in caregivers who had sought traditional help ($p < 0.01$), provided supernatural explanations for their child's condition ($p = .02$) and in caregivers of Orthodox Christian faith ($p = .03$). Caregivers gave a mixture of biomedical explanations (e.g. head injury (30.4 %) or birth complications (25.5 %)) and supernatural explanations (e.g. spirit possession (40.2 %) or sinful act (27.5 %)) for their child's condition. The biggest reported unmet need was educational provision for their child (74.5 %), followed by treatment by a health professional (47.1 %), financial support (30.4 %) and expert help to support their child's development (27.5 %). Most caregivers reported that talking to health professionals (86.3 %) and family (85.3 %) helped them to cope. Many caregivers also used support from friends (76.5 %) and prayer (57.8 %) as coping mechanisms.

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Conclusions: This study highlights the stigma experienced by families caring for a child with a developmental disorder. Designing interventions appropriate for low-income settings that improve awareness about developmental disorders, decrease stigma, improve access to appropriate education and strengthen caregivers' support are needed.

Keywords: Stigma, Developmental disorder, Autism Spectrum Disorder, Intellectual disability, Developing countries, Africa

Background

Epidemiological studies in low- and middle-income countries of the prevalence of child mental health problems, including developmental disorders, indicate that these conditions are at least as prevalent as in high-income countries [1]. In a meta-analysis, the prevalence of intellectual disability (ID) was higher in low-income countries (1.6 %) than in high-income countries (1.0 %) [2]. The global prevalence of autism spectrum disorder (ASD) is estimated to be around 0.6 %, but there are no prevalence data available from anywhere in Africa [3]. ASD and ID are lifelong developmental disorders that have a large impact not only on the individual but also on the caregivers [4]. The challenges experienced by caregivers of children with ASD or ID have been relatively well documented in high-income countries [5–8], but less is known about the experiences of caregivers from low- and middle-income countries [9–12].

Studies from high-income [5–8] and low- and middle-income countries [9, 11] have shown that families with children with autism or ID frequently experience stigma. Both felt stigma (referring to feelings of shame and the anticipation of prejudice that prevents people from talking about their experiences and impedes them looking for help) and enacted stigma (external stigma, such as evasion and discrimination) are common [13]. In India, caregivers indicated that they would be ashamed if people knew someone in their family had been diagnosed with autism [11]. In Tanzania, caregivers of children with mental illness, including ID and ASD, reported that they experienced social exclusion and discrimination [9]. Another challenge identified in previous studies is that caregivers may hold misconceptions about the perceived causes and prognosis of developmental disorder in their children [14]. Severe mental disorders [15] and autism [16] are frequently attributed to supernatural or traditional forces in sub-Saharan Africa [15] and in Asia [14]; these forces may include lineage curses, enemies, an action of the devil, or a punishment from God [15, 16].

Studies in high-income countries [8, 14, 17], India [11] and among Indian parents living abroad [18] have found that caregivers of a child with a developmental disorder tend to utilise a wide variety of treatment strategies, including biomedical as well as traditional or alternative and complementary treatments. Many caregivers also report financial difficulties, either directly, due to the costs of the treatment sought [9, 14], or indirectly, because of caregivers foregoing opportunities to engage in income generating activities [9]. In studies from high-income [8, 14] and low- and middle-income countries [9, 11, 19] caregivers have been reported to respond actively to the challenges they faced through a range of approaches: talking to a health professional, family members or religious leaders, praying and employing spiritual practices and accessing instrumental social support.

Although these previous studies have provided important insights, the challenges experienced by caregivers of children with ASD and ID have not been fully understood or described in different socio-cultural contexts. Studies in sub-Saharan Africa focusing on developmental disorders are especially rare. A study from Nigeria investigated healthcare worker perspectives on autism [16] and a qualitative study from Kenya explored the perceptions of both professionals and parents [20]. Three further studies from Africa have explored parental views [9, 21] or views from a general population sample [15] in relation to general mental health problems rather than developmental disorders specifically. Moreover, many of the previous studies in low- and middle-income countries were purely qualitative and were thus unable to compare groups statistically [9, 11, 13].

In Ethiopia, as in many other low-income countries, there are limited services for children with developmental disorders and their caregivers [12]. Out of a population of over 90 million people, nearly half of whom are children, there are only two trained child psychiatrists and the available specialised child mental health clinics are limited to the capital city, Addis Ababa. In planning future intervention programmes for children with developmental disorders it is essential to better understand the perspective of the caregivers. The aim of the present study was to describe the experiences and challenges of caring for children with ASD and/or ID among caregivers, particularly in terms of examining stigma experienced by families, understanding the perceived causes of the illness, mapping out the interventions tried and coping strategies practiced as well as determining the unmet

needs of caregivers. A good understanding of these factors is essential for designing and implementing future interventions for Ethiopia and other low resource settings to improve the lives of children with developmental disorders and their families.

Methods

Setting

The study was conducted at the child mental health clinics at Yekatit 12 Hospital Medical College ("Yekatit 12 Hospital") and St. Paul's Specialised Hospital Millennium Medical College ("St Paul's Hospital") in Addis Ababa, the capital city of Ethiopia. Yekatit 12 and St. Paul's hospitals are the only two public referral hospitals in Ethiopia with specialist expertise in child developmental disorders. Both hospitals provide out-patient child mental services for children with ASD and/or ID, including diagnostic assessment, medication where appropriate, signposting to available community services and ongoing follow-up.

Study design

A cross-sectional facility-based study was carried out using a structured questionnaire administered in a face-to-face interview to caregivers of children with ASD and/or ID.

Participants

The study population consisted of all caregivers of children under 18 years of age with a clinical diagnosis of ASD and/or ID, attending the child mental health clinics of each hospital over a period of four months. Registration records were reviewed each day to select participants who were eligible for the study. Caregivers were excluded from being invited to take part if the child was acutely disturbed or in need of emergency medical intervention. Consecutive attendees of the child mental health clinics caring for a child diagnosed with ASD and/or ID were approached to participate; all invited caregivers ($n = 102$) agreed to take part (participation rate 100 %). Diagnoses were made by a child psychiatrist and/or psychiatrist trainees following DSM-IV criteria, after a clinical observation and an interview with the child's caregiver. The medical case notes of the child of each participating caregiver were consulted to determine the primary diagnosis of the child (ID or ASD).

Measures

The structured questionnaire comprised five parts: socio-demographic characteristics, family experience of stigma, explanatory model of illness, type of intervention used or desired and caregiver coping strategies. The socio-demographic section collected information on the age, marital status, religion, ethnicity, and education status of the respondent. The family's experience of stigma in the community was measured using an adapted version of the Family Interview Schedule (FIS) [22]. The FIS includes 14 questions about the family's experience of stigma in the community. The original version of the FIS was developed for relatives of people with schizophrenia and was therefore adapted for use in this study to focus on caregivers of children with developmental disorders. An adapted version of the FIS has previously been used in Ethiopia to assess stigma in relatives of individuals with schizophrenia or major affective disorder [23]. In keeping with the version used in that study (and in contrast to the original FIS, which used a visual analogue scale), each FIS question in our survey was rated on a four-point scale where experiencing stigma in the community 'a lot' was given a score of 3, 'often' a score of 2, 'sometimes' a score of 1, and 'not at all' a score of 0. To assess the distribution of responses between groups, a total score was computed by summing the item scores, with a minimum score of 0 and a maximum score of 42. The internal consistency of this adapted FIS scale was good (Cronbach's Alpha = 0.92). The other sections of the fully structured questionnaire contained questions concerning explanatory models of illness, the perceived severity and prognosis of their child's condition, interventions tried, coping strategies used and questions about service utilisation. The answer categories included in these closed questions were based on previous international autism studies as well as previous mental health studies in Ethiopia, and tested prior to data collection in a pre-test (please see below for more information). Each closed question also included the answer category 'other' (with free text specification) to allow for any answers not fitting in the pre-specified answer categories. Lastly, the type of support most needed to help improve the child's condition was explored through an open-ended question: 'To help your child with slow development to improve, what would help the most?'

Data collection

The questionnaire was prepared in English, translated into Amharic and then back-translated into English to ensure consistency. The instrument was pre-tested by the first author in caregivers of children with ASD and/or ID in attendance at the child mental health clinic at Yekatit 12 Hospital and also in a group of caregivers of children attending the Nehemia Autism Centre, a centre for children with ASD in Addis Ababa. A final version of the questionnaire was established following feedback from the pre-test. Psychiatric nurses were trained to administer the questionnaire by conducting face-to-face interviews with respondents. Training was given over two days to ensure that the psychiatric nurses were familiar

with the data collection procedures, the questionnaire, information sheets and consent forms. All completed questionnaires were checked for completeness, accuracy, clarity and consistency by the first author.

Data management

Double data entry using Epidata version 3.1 [24]was employed to reduce the risk of data errors. The data were then exported to SPSS version 20 (IBM SPSS Statistics 20) for analysis.

Data analysis

Responses to the open-ended question on support most needed were grouped following broad answer categories. The frequency distribution of all closed-ended variables was examined to check for any outliers and to see the overall distribution. The FIS total score was found to be normally distributed, permitting subsequent parametric analyses. Using stepwise multiple linear regression it was tested whether any of the demographic, clinical or explanatory model and service use related variables could predict FIS sum scores. Non-parametric Mann–Whitney tests were used to examine whether scores on individual stigma items were related to the type of developmental disorder (ID vs ASD). Results were interpreted as significant when $p < 0.05$.

Ethical considerations

Ethical approval was obtained from the Institutional Review Board of the College of Health Sciences of Addis Ababa University and the Human Research Ethics Committee of the Open University (UK). Authorisation from both child mental health clinics was obtained. All study participants were informed about the purpose of the study and written informed consent was secured from all participants prior to the start of data collection.

Results

Demographic characteristics

Data were available for 102 participants. The mean age of the respondents was 36.9 years (SD = 8.9); the majority were Orthodox Christians ($n = 73$; 71.6 %), married ($n = 70$; 68.6 %), were urban residents ($n = 82$; 80.4 %) and housewives ($n = 49$; 48.0 %). About a fifth of the respondents ($n = 22$; 21.6 %) were uneducated; 60.8 % ($n = 62$) had received at least some formal education (ranging from any primary (grade 1-8) to any secondary school education (grade 9-12); the remaining caregivers ($n = 18$; 17.6 %) had completed a form of tertiary education. See Table 1. Among the cases, 68 children (66.7 %) had a diagnosis of ID and 34 children (33.3 %) had ASD as their primary diagnosis. The medical case notes of 10 out of 34 children with ASD explicitly mentioned that they had co-comorbid ID, but this is likely to be an underestimate of co-morbidity as high functioning cases of ASD are rarely diagnosed in Ethiopia. The mean age of children with developmental disorder was 8.2 ± 3.3 years. Most of the children ($n = 77$; 75.5 %) were male. Of the 102 caregivers of children with developmental disorder, five (4.9 %) had one or more other children with developmental problems (Table 1).

Experienced stigma and explanatory models

Caregivers endorsed experience of stigma on many items of the adapted FIS (see Fig. 1). For example, 44 out of 102 participants (43.1 %) indicated they worried 'sometimes' 'often' or 'a lot' about being treated differently. Likewise, many felt ashamed or embarrassed about their child's condition ($n = 46$; 45.1 %), felt a need to hide the problem from people in the community ($n = 27$; 26.4 %), or made an effort to keep their child's condition a secret ($n = 27$ out of 101 responses; 26.7 %), worried that people would be reluctant to marry into their family ($n = 25$; 24.7 %) and worried about taking their child out of the house ($n = 40$; 39.3 %). Other experiences of caregivers included feeling depressed about their child's condition ($n = 71$; 69.6 %), seeking caregivers of a child with similar problems ($n = 51$ out of 101 responses; 50.5 %), feeling that their child's problem is their fault ($n = 48$; 47.1 %) and explaining to others that their child does not fit typical cultural stereotypes of mentally ill individuals ($n = 46$; 45.1 %) (Fig. 1).

Caregivers cited a mixture of biological and supernatural factors as causes for their child's condition (Table 2). The most common biomedical explanations were head injury ($n = 31$; 30.4 %), birth complications ($n = 26$; 25.5 %), epilepsy ($n = 21$; 20.6 %), pathogens ($n = 12$; 11.8 %) and a family history ($n = 12$; 11.8 %). Frequently cited supernatural explanations included spirit possession (a spirit taking control over one's thinking and actions; $n = 41$; 40.2 %), a sinful act (a direct result of the caregiver's transgression $n = 28$; 27.5 %), punishment from God (specific attribution of the consequence of a sinful act to punishment from God $n = 26$; 25.5 %), evil eye or *"buda"* (a spell cast by the eye, inflicting injury or misfortune on the person being looked at; $n = 20$; 19.6 %), and curse or bewitchment (harm inflicted by magical acts or supernatural powers instigated by another person or by supernatural beings; $n = 10$; 9.8 %). Over half ($n = 56$; 54.9 %) of respondents gave at least one supernatural causal explanation, while 59.8 % ($n = 61$) gave at least one biomedical explanation. Biomedical and supernatural causal explanations were not mutually exclusive, with 37 participants (36.3 %) providing both biomedical and supernatural explanations.

Even though the majority ($n = 69$; 67.6 %) of participants believed that their child's developmental problems were very or quite severe, most of the respondents ($n = 94$;

Table 1 Demographic and clinical characteristics of the respondents and association with scores on the adapted Family Interview Schedule (FIS) stigma scale

	Characteristic	*N* (%)	Mean FIS score	Standardised B coefficient	t-value	*p*-value
Caregiver characteristics						
Age (years)	Mean age 36.9 years					
	<25	9 (8.8)	14.9			
	25-34	30 (29.4)	10.5			
	35-44	41 (40.2)	12.8			
	≥45	22 (21.6)	12.2			
Religion	Orthodox	73 (71.6)	13.9	.21	2.23	.028
	Protestant	16 (15.7)	6.6			
	Muslim	13 (12.7)	9.7			
Marital status	Married	70 (68.6)	11.0			
	Never married	9 (8.8)	11.7			
	Formerly married	12 (11.8)	18.3			
	Not applicable	11 (10.8)	13.5			
Level of education	No formal education	22 (21.6)	13.8			
	Completed grade (1-12)	62 (60.8)	11.6			
	Diploma and above	18 (17.6)	8.4			
Occupation	Farmer	11 (10.8)	9.9			
	Housewife	49 (48.0)	13.2			
	Employed	34 (33.3)	10.7			
	Unemployed	8 (7.8)	13.9			
Residence	Urban	82 (80.4)	12.4			
	Rural	20 (19.6)	11.6			
Child characteristics						
Age of child with developmental disorder	Mean age 8.2 years					
	1-6 years	32 (31.4)	11.4			
	7-12 years	61 (59.8)	11.8			
	13-18 years	9 (8.8)	17.6			
Gender	Boy	77 (75.5)	11.5			
	Girl	25 (24.5)	14.4			
Siblings with developmental problems	No	97 (95.1)	12.3			
	Yes	5 (4.9)	10.8			
Type of developmental disorder	Autism spectrum disorder	34 (33.3)	11.9			
	Intellectual disability	68 (66.7)	12.3			
Caregiver explanatory models						
Supernatural causal explanation	No	46 (45.1)	9.2			
	Yes	56 (54.9)	14.6	.22	2.40	.018
Biomedical causal explanation	No	41 (40.2)	10.2			
	Yes	61 (59.8)	13.6			
First looked for help	Traditional institution	56 (54.9)	10.7			
	Biomedical institution	46 (45.1)	14.0			
Ever sought help from traditional institution	No	34 (33.3)	7.0			
	Yes	68 (66.7)	14.8	.27	2.95	.004

Table 1 Demographic and clinical characteristics of the respondents and association with scores on the adapted Family Interview Schedule (FIS) stigma scale *(Continued)*

Traditional treatment tried	No	42 (41.2)	8.8
	Yes	60 (58.8)	14.6
Biomedical treatment tried	No	61 (59.8)	12.4
	Yes	41 (40.2)	11.9

Note: *FIS* Family Interview Schedule; the original FIS was adapted to be appropriate for caregivers of children with developmental disorders

92.2 %) believed that their child's problems could be cured. Only a minority of respondents thought that their child's condition could be transmitted to other people ($n = 7$; 6.9 %). A slightly higher number ($n = 12$, 11.8 %) indicated that other people thought their child's condition was contagious (Table 3).

Traditional and biomedical support sought

When asked where they went to seek help for their child, more than half of the caregivers indicated they first sought help from traditional places ($n = 56$; 54.9 %), while just under half of the participants first approached a biomedical institution ($n = 46$; 45.1 %). When asked what other types of help they had sought prior to coming to the current child mental health clinic, the majority had attended a hospital ($n = 83$; 81.4 %) and/or a private clinic ($n = 27$; 26.5 %), and many had visited traditional institutions, including centres for religious healing (e.g. holy water ($n = 53$; 52.0 %), a church or priest ($n = 35$; 34.3 %)) or different types of traditional healers (Table 4).

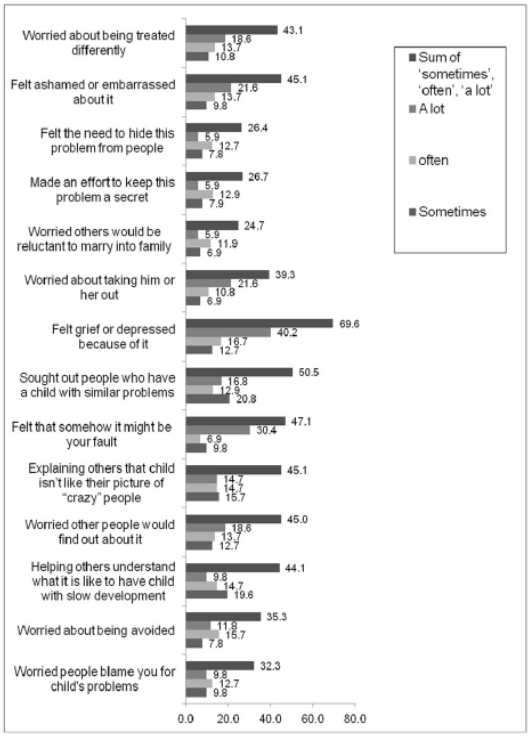

Fig. 1 Pattern of positive responses on the Family Interview Schedule questionnaire in caregivers of children with developmental disorders

Type of interventions tried

Caregivers reported using both biomedical treatments (tablets ($n = 40$; 39.2 %) or injections ($n = 4$; 3.9 %) received through a health facility) and traditional interventions (prayer ($n = 48$; 47.1 %), *kitab* (a written script tied on the arm or neck; $n = 8$; 7.8 %), slaughtering a sheep ($n = 4$; 3.9 %), or fumigating (making excessive use of smoke by burning incense; $n = 2$; 2.0 %)) as treatment interventions. A subgroup of caregivers also indicated they had used beating ($n = 19$; 18.6 %) or chaining ($n = 9$; 8.8 %) to manage their child (Additional file 1: Table S1). Many ($n = 27$, 26.5 %) caregivers had tried both traditional and biomedical treatment for their child.

Table 1 summarises the results of the analyses examining the association of demographic and clinical characteristics with the sum score of the adapted FIS, using stepwise multiple regression. The experience of stigma, as indicated by the FIS sum score, was associated with caregivers providing a supernatural causal explanation

Table 2 Caregiver perceived causes of developmental disorder in the child[a]

Perceived causes of child developmental disorder	Number	Percent
Spirit possession	41	40.2
Sinful act	28	27.5
Punishment from God	26	25.5
Evil eye	20	19.6
Curse/bewitchment	10	9.8
Head injury	31	30.4
Birth complications	26	25.5
Epilepsy	21	20.6
Pathogen/infectious cause	12	11.8
Family history	12	11.8
Drinking alcohol in pregnancy	3	2.9
Chewing *Catha edulis* (khat) in pregnancy	2	2.0

[a]Respondents could provide multiple answers

Table 3 Caregiver perceptions about the child with a developmental disorder

Variable	Number	Percent
Believe that child's problems with autism/ID can be cured		
Yes, cured	94	92.2
Not cured, but improved	8	7.8
No cure or improvement	0	0
How severe do you think your child's problem with developing slowly is?		
Very severe	44	43.1
Quite severe	25	24.5
Not too severe	25	24.5
Not severe at all	8	7.8
Do you think your child's condition can be transmitted to other people?		
No	95	93.1
Yes	7	6.9
Do you think other people think that your child's condition can be transmitted to other people?		
No	90	88.2
Yes	12	11.8

($p = 0.02$), but not associated with a biomedical causal explanation ($p > 0.05$). Moreover, experienced stigma was significantly higher in caregivers of Orthodox Christian faith ($p = .03$) and in caregivers who had sought help from traditional institutions ($p < 0.01$). Having included 'help sought from traditional institution' in the regression model, the variable 'tried traditional treatments' did not contribute significant additional predictive information ($p > .05$). Likewise, whether caregivers had ever tried biomedical treatments and whether families first looked for help from a biomedical or traditional institution was not associated with the FIS score (both $p > .05$). The FIS total score also did not depend on the type of developmental disorder (ID vs. ASD), the child's age or gender,

Table 4 Help-seeking by caregivers of a child with developmental disorder

Help-seeking	Number	Percent
First place where help sought		
Biomedical (modern health institution)	46	45.1
Traditional	56	54.9
Have you ever looked for help from any of the following[a]		
Holy water	53	52.0
Church/priest	35	34.3
Debtera (spiritual healers in Orthodox Christian clergy)	7	6.9
Herbalist	11	10.8
Mosque	9	8.8
Kalicha (spiritual healers in Muslim clergy)	6	5.9
Tanquaye (Sorcerer)	5	4.9
Wogesha (traditional physical therapy including massage and bone setting)	5	4.9
Hospital	83	81.4
Private clinic	27	26.5
Public health centre	22	21.6
Health extension workers	6	5.9
Private pharmacy	6	5.9
Broad classification of help sought		
Ever sought traditional help	68	66.7

Note: [a] Respondents could provide multiple answers

the age or level of education of the caregiver or whether the family lived in a rural or urban area (all $p > 0.05$). Finally, when considering each stigma item in isolation, no difference in reported stigma was found in relation to type of developmental disorder (all $p > 0.05$).

Unmet need

The most common unmet needs expressed by caregivers were appropriate educational provision for their child ($n = 76$; 74.5 %), treatment by a health professional ($n = 48$; 47.1), financial support (for instance to buy food) ($n = 31$; 30.4 %), access to support from professionals in managing their child and supporting their child's skills development ($n = 28$; 27.5 %) and access to expert information and advice about their child's condition ($n = 23$; 22.5 %) (Additional file 1: Table S1). All responses concerned desired support from outside rather than within the family. The phrasing of the question ('To help your child with slow development to improve, what would help the most?'), with its focus on support to *improve* the child's development, is likely to have contributed to respondents referring to external support.

Coping strategies

Various coping mechanisms, including talking to someone, seeking religious help and using substances/drugs, were used to deal with emotional difficulties arising as a result of caring for a child with ASD or ID. Caregivers most often spoke to a health professional ($n = 88$; 86.3 %), talked to family members ($n = 87$; 85.3 %) or talked to friends ($n = 78$; 76.5 %), and also often used prayer ($n = 59$; 57.8 %) as a coping strategy. Adverse coping strategies such as chewing *Catha edulis* (khat) ($n = 5$; 4.9 %), drinking alcohol ($n = 4$; 3.9 %) and smoking cigarettes ($n = 3$; 2.9 %) were used by a minority of respondents (Additional file 1: Table S1).

Gateway to the clinic

The most common source of information that had led the family to attend the child mental health clinic was a community-based health extension worker, with 52.9 % of caregivers citing their help in finding the way to the clinic (Fig. 2).

Discussion

High levels of stigma experienced by caregivers

This study indicates that stigma experienced by caregivers, including worrying about being treated differently, feeling ashamed or embarrassed about their child's condition, making an effort to keep their child's condition a secret and explaining to others that their child does not fit stereotypical conceptions of mental illness or 'madness', are common among caregivers of children with ASD or ID. Other experiences, such as feeling depressed, seeking out other people caring for a child with similar problems, or feeling that the problem is their fault are also common. This finding is consistent with research conducted in high-income countries that indicated the majority of caregivers experienced felt stigma [5–8, 14]. Our study findings were also in accordance with other studies conducted in low- and middle-income countries, namely that caregivers of children with developmental disorders often experienced embarrassment, shame and guilt [9, 11, 13, 23]. In a previous study in Ethiopia that assessed stigma using the FIS in relatives of people with schizophrenia or major affective disorder found similarly high levels of stigma [23]. Investigators from India, Tanzania and China reported that the majority of caregivers of children with developmental disorders felt tired, depressed, exhausted and worried about their child's future role in society [9, 11, 19]. However, these studies were purely qualitative and were unable to examine quantitatively which factors may be associated with stigma. Our findings suggest that caregivers seeking help from traditional institutions experience significantly higher levels of stigma than caregivers who did not seek this type of support. Moreover, Orthodox Christian religion and providing a supernatural explanation for the child's problems were predictive of high reported stigma. As this is a cross-sectional study, it was not possible to examine the direction of causation of the association between traditional support and stigma experienced. That is, it remains unclear whether engaging with traditional institutions may increase experienced stigma, or whether families who experience high levels of stigma are more inclined to seek support from traditional institutions.

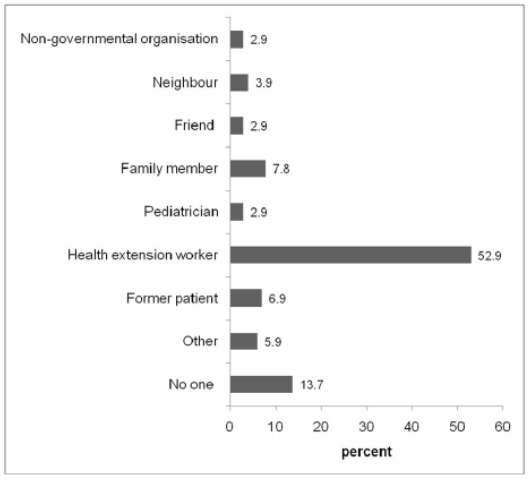

Fig. 2 Source of information leading to attendance of caregiver at child mental health clinic

Explanatory model of illness for caregivers

In this study, caregivers cited a mix of biomedical and supernatural factors as causes for their child's condition. Many caregivers reported that they perceived both supernatural factors, such as spirit possession, the result of a sinful act or punishment from God, and biomedical factors, such as a head injury, birth complications, or epilepsy to be the cause of their child's developmental disorder. This result is consistent with studies in Taiwanese parents [14] and Indian parents living abroad [18], who also reported a mix of biomedical and supernatural causes of their child's condition. Similarly, in a previous study from Ethiopia, where the explanatory models of parents of in-school children for child mental disorders were investigated, the majority endorsed both biomedical and supernatural courses [21]. These results suggest that supernatural and biomedical belief systems often co-exist. It should be noted that, given that all study participants were recruited from a specialist referral hospital, selection bias may have led to a higher proportion of participants from our study endorsing biomedical causes than may be observed in the general Ethiopian population.

Most respondents (92.2 %) in this study believed the child's condition to be curable. This finding suggests caregivers may have somewhat unrealistic expectations of what can be achieved with interventions or treatment, perhaps suggesting a risk for dissatisfaction among caregivers with the outcome for future interventions. However, 'social desirability' bias may also have played a role: since the study was conducted in a mental health clinic and the data collectors were psychiatric nurses, caregivers may have been inclined to over emphasise their belief in a (biomedical) cure. A further explanation for the strong confidence in curability could be religious beliefs. A study carried out among South Asian Muslim immigrant families reported that families understood the task of raising a child with autism in religious terms [25]. In that study, parents reported that keeping to the precepts of Islam would help them to raise their developmentally disabled children as normally as possible. The high level of belief in curability in our study may similarly be explained by the fact that Ethiopia is a deeply religious society. Reflective of Ethiopian society as a whole, all our participants were religious and not believing in a cure could be understood as questioning the power of God. In the Kenyan study, parents of children with ASD reported that they hoped for a cure and sought treatment with this expectation in mind [20].

The majority (67.6 %) of the participants in this study indicated that they believed their child's developmental disorder to be very or quite severe. In the Ethiopian context, where access to child mental health services is extremely limited, only the more severe cases will reach the clinic. Therefore our sample is likely to include more severe cases of developmental disorders than the full ID and ASD spectrum that may attend clinics in better resourced countries. As there are no validated tests of intellectual ability for use in Ethiopia it was impossible to provide a quantitative description of the extent of childrens' developmental disability.

Interventions tried by caregivers

Many caregivers indicated they used a combination of traditional and biomedical interventions to help their child. This is comparable to studies done in high-income countries [8, 14] that reported caregivers used multiple services and treatment strategies to help their developmentally disabled child including psychological, medical and paramedical services [8], as well as special diets and traditional treatments [14, 18]. For example in Taiwan parents reported engaging in spiritual rituals such as paying a monk to read the Buddhist Bible and changing the name of the child to change his "fate". Similarly, our study found rituals related to the prevalent religions in Ethiopia (Orthodox and protestant Christianity and Islam) and traditional belief systems to be common. The wide range of interventions tried by caregivers may reflect the fact ASD and ID are lifelong conditions, so caregivers keep looking for answers and treatments.

A considerable minority of caregivers indicated they have beaten (18.6 %) or chained (8.8 %) their child to manage their child's problems. Beating a child in an attempt to teach them to improve their behaviour is still common in Ethiopia. However, in a study in which we interviewed service providers for children with autism [12] it was highlighted that chaining is usually done not as a punishment, but to protect the child from harming themselves or others when there is no-one to look after the child. Interventions are urgently needed to support families in the community and to discourage harmful practices such as beating and chaining.

Unmet needs of caregivers

The majority of caregivers (74.5 %) indicated an unmet need for appropriate educational provision for their child, followed by treatment by a health professional (47.1 %). In addition many caregivers expressed they needed financial support (30.4 %), access to professionals to help support their child's behaviour and skills development (27.5 %) and access to expert information and advice about their child's condition (22.5 %). These perceived needs of caregivers in our study are comparable to studies from high-income countries [8, 10], in which the majority expressed a need for educational services, health service provision, support for social activities, and access to information. A systematic review of studies conducted in Brazil indicated a similar set of unmet

needs [26]. Likewise, a study conducted in Tanzania [9] indicated that caregivers expressed a desire for support with schooling, professional assistance, health education and information, and social supports. This common set of unmet needs reported by caregivers among different studies is likely to be because of the similarity of the behaviours or needs of children with ASD or ID regardless of the setting they live in. However, the service provision for children with developmental disorder in high-income countries is rather different from the provision available in most low- and middle-income countries. Even though the provision may be perceived as inadequate most children in high-income countries will get some type of support and special education (although stark differences may exist between socioeconomic groups). In contrast, in Ethiopia most children with developmental disorders do not get any provision; most remain undiagnosed and specialist schooling and intervention is unavailable in rural areas, where 85 % of the population lives [12]. Although the service provision for children with developmental disorders in low- and middle-income countries is not well-documented, the challenges reported in Ethiopia are likely to also apply to other low resource countries and settings.

Coping strategies for caregivers

The most common coping mechanisms used by caregivers in our study were talking to health professionals, talking with family or friends and prayer. This result is consistent with a systematic review of coping strategies of families affected by autism in Brazil, where caregivers were assisted by access to medical care, information exchange between families and seeking religious support [26]. Talking to family and friends was another important coping mechanism reported frequently by parents from the Philippines [27] and in studies conducted in high-income countries [10, 18, 28]. Our study indicated more than half (57.8 %) of the respondents reported prayer as a coping mechanism, reflecting the importance of religious faith within society. This finding also highlights that, while seeking help from traditional institutions was related to higher experienced stigma, many caregivers find support in their religious beliefs and rituals through prayer. In a study from the Philippines, religion and spiritual practices seemed to provide positive social support for parents of developmentally disabled children; church members offered emotional support, guidance, frequent company and acceptance of their children [27]. In a study from rural Ethiopia in relatives of people with schizophrenia many relatives were also inclined towards prayer for guidance and talking with someone about their problems as a coping mechanism [29]. Similar to our findings the study participants valued their contact with health professionals in enabling them to cope. This might be a reflection of the high status of health professionals in Ethiopia and indicates an important role of the health sector in supporting caregivers of children with child developmental disorders.

Gateway to the clinic

In the majority of cases (52.9 %) the family found their way to the clinic through referral by a health extension worker. Health extension workers provide basic health services in the local community. Since 2003 the Ethiopian government has trained 39,000 of these community health workers, with two health extension workers deployed in each community. Our study suggests that these workers play an important role in identifying developmental disorders and thus form a gateway to specialised help. As part of our HEAT+ research project we are currently evaluating the impact of brief mental health training for health extension workers in improving awareness of mental health problems and developmental disorders [30]. This training aims to improve the detection of developmental disorders in the rural areas of Ethiopia (where most health extension workers are deployed) and to help decrease stigma in the community by equipping the health worker with the skills and knowledge needed to raise mental health awareness in the local community.

Limitations and strengths

Limitations of the study include that the respondents lived primarily in urban areas; the findings may not be generalisable to more rural settings in Ethiopia. The study was facility-based, and thus was biased towards those with higher educational level and ability to access biomedical care. The experiences of these caregivers may differ from families whose child with similar problems has not (yet) been diagnosed. We were not able to determine how long ago the caregivers were first informed of their child's diagnosis, nor since how long the caregivers had been concerned about their child's development. The perspectives of caregivers who have long been aware of their child's condition may be different from those who have only recently become aware their child's development is atypical. Also, our sample of caregivers of a child with ASD was small, providing limited power to compare the stigma associated with to that of ID only. Additionally, the cross-sectional study design restricts our ability to draw causal or temporal associations. Lastly, since the study was conducted by psychiatric nurses and touches on potentially sensitive issues, the possibility that respondents reported information based on their perception of what the interviewer wanted to hear (i.e. a 'social desirability' bias) cannot be excluded. However, the study is the first study in Ethiopia among the caregivers of children with ASD or

ID and provides information in an area of public health of which very little is known, not just in Ethiopia, but in sub-Saharan Africa more widely. Moreover the high participation of participants and high consistency with other studies in caregivers of children with developmental disorders supports the reliability of our findings.

Implications

This research has a number of implications for professionals working with caregivers and children with developmental disorders in Ethiopia and other low resource settings. First, in response to the high levels of felt stigma in caregivers, there is a need to design interventions to improve public awareness about developmental disorders, decrease stigma and improve access to appropriate services. Second, in response to the finding that stigma experience was significantly stronger in caregivers who had sought help from traditional institutions, there is a need to work collaboratively with traditional and faith healers, for example by organising joint public awareness and anti-stigma efforts with these traditional institutions [31]. We do not advocate discouraging seeking help from traditional and religious institutions, as many caregivers feel supported by these systems, also illustrated by the high percentage of caregivers indicating they used prayer as a coping strategy. Third, we also found that many parents hold both supernatural and biomedical causal beliefs and that the two aetiologies are not mutually exclusive, with most participants giving both biomedical and supernatural explanations. Based on this finding, it is necessary to train healthcare providers to be empathetic to the needs and conditions of caregivers and be open to the possibility of collaborative engagement with traditional healers for the holistic care of children with developmental disorders [31]. Health professionals need to respect caregivers' beliefs and supernatural explanations, while also sensitively providing psycho- education on causes and helpful strategies to support their child, and discourage harmful practices such as beating and chaining. Fourth, the finding that caregivers' coping mechanisms include talking to health professionals, family and friends as a main mechanism to cope the problems can help professionals to prepare different strategies in counselling and the delivery of psychosocial interventions. In low-resource settings such as Ethiopia community-based psychosocial interventions delivered by non-specialists (e.g. community health workers, primary care workers or peers) are a viable strategy to scale-up support for families with children with developmental disorders [32]. Though, since most parents believe their child can be cured, this expectation of a cure needs to be born in mind when designing a psychosocial intervention. Fifth, the finding that health extension workers form the main gateway to access to biomedical services highlights the importance of increasing awareness of developmental disorders among health extension workers to increase identification of ASD and ID in the local community.

Conclusion

Caregivers of children with ASD or ID in Ethiopia face many challenges, including high levels of stigma and a lack of appropriate provision for their child. Reported stigma was significantly stronger in caregivers who had sought help from traditional institutions or had supernatural explanations for their child's condition. The study has implications for policies to reduce stigma, increase awareness about the causes of developmental disorders and address the needs of caregivers of developmentally disabled children. Interventions to improve awareness about developmental disorders, to decrease stigma, and improve access to appropriate education and support for caregivers are warranted.

Ethics approval and consent to participate

Ethical approval was obtained from the Institutional Review Board of the College of Health Sciences of Addis Ababa University and the Human Research Ethics Committee of the Open University (UK). Authorisation from both child mental health clinics was obtained. All study participants were informed about the purpose of the study and written informed consent was secured from all participants prior to the start of data collection.

Consent for publication

Not applicable.

Availability of data and materials

The dataset will not be shared because it is being used for an ongoing PhD thesis.

Additional file

Additional file 1: Table S1. Type of treatment tried, unmet needs and coping mechanisms of caregivers of children with developmental disorders. (DOCX 13 kb)

Abbreviations

ASD: autism spectrum disorder; FIS: family interview schedule; ID: intellectual disability.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

DT, CH, RH, AF and YB all contributed to the study design, DT conducted the study, supervised in the field by CH, RH, AF, YB and BT. DT, CH, RH and AF analysed the data. DT wrote the first draft of the manuscript. All authors contributed to interpretation of the study findings. All authors reviewed and approved the final manuscript prior to submission.

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Annex 1.2. Tilahun D, Hanlon C, Araya M, Davey B, Hoekstra RA, Fekadu A. Training needs and perspective of health extension workers in relation to integrating child mental health care in to primary health care service in a rural setting of sub-Saharan Africa. *Int J Ment Health Syst (2017) 11:15* DOI 10.1186/s13033-017-0121-y (**published**).

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Training needs and perspectives of community health workers in relation to integrating child mental health care into primary health care in a rural setting in sub-Saharan Africa: a mixed methods study

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Abstract

Background: Community health workers can help to address the substantial unmet need for child mental health care in low and middle income countries. However, little is known about their training needs for this potential role. The aim of this study was to examine training needs and perspectives of community health extension workers (HEWs) in relation to providing child mental health care in rural Ethiopia.

Methods: The study was conducted in the Southern Nations, Nationalities and Peoples' Region of Ethiopia. A mixed methods approach was used. A total of 104 HEWs who had received training in child mental health using the Health Education and Training (HEAT) curriculum were interviewed using a structured survey. In-depth interviews were then conducted with 11 HEWs purposively selected on the basis of the administrative zone they had come from. A framework approach was used for qualitative data analysis.

Results: Most of the HEWs (88.5%; n = 93/104) reported that they were interested in the training provided and all respondents considered child mental health to be important. The perceived benefits of training included improved knowledge (n = 52), case identification (n = 14) and service provision (n = 22). While most of the participants had their training four months prior to the interview, over a third of them (35.6%; n = 37) had already organized mental health awareness-raising meetings. Participants in the qualitative interviews considered the problem of child mental disorders to be widespread and to cause a large burden to the family and the affected children. They reported that improving their competence and knowledge was important to address the problem and to tackle stigma and discrimination. Participants also listed some barriers for service provision, including lack of competence, stigma and institutional constraints. Opportunities mentioned included staff commitment, high levels of interest and a positive attitude towards providing the service.

Conclusions: Although the HEAT training on child mental health was brief, it appears to have had some impact in improving knowledge and care provision. If the key barriers to service provision are addressed and supported by policy guidance, community health workers may contribute substantially in addressing the treatment gap for children with mental health needs.

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Keywords: Developmental disabilities, Community health workers, Primary health care, Developing countries, Africa, Ethiopia

Background

Globally, 10 to 20% of children are estimated to have mental health problems [1, 2]. In Ethiopia, childhood mental problems have been found to affect 12–25% of children [3–5]; these problems are found to be associated with disability, cost and poorer quality of life of children and their families [1, 2, 6–8]. Moreover, the treatment gap approaches 90% in low and middle income countries (LMIC), largely due to lack of detection of these problems and a severe shortage of trained manpower [9, 10].

Community health extension workers (HEWs) have the potential to play a major role in addressing the treatment gap in LMIC [6, 11, 12]. There is clear evidence of the beneficial role of community health workers in promoting immunization uptake, improving outcomes for acute respiratory infections and malaria care in LMIC [13–16]. There is also evidence that identification and treatment of mental disorders may be improved through training of HEWs [9, 17–19]. Delivery of integrated care at the primary health care (PHC) level supported by HEWs may even reduce stigma and discrimination [17, 19–21]. However, at present there is insufficient evidence to justify recommendations for the deployment of community health workers for child mental health care.

In Ethiopia, the health extension program was launched in 2003 [22]. Since that time, around 38,000 HEWs have been deployed to rural areas across the country. HEWs are mostly female health workers tasked mainly with providing promotive, preventive and rehabilitative care after one year of training. More specifically, HEWs in Ethiopia promote immunization uptake, antenatal care and prevention of malaria, both at their health post and through outreach services by visiting the houses of people in their community [23, 24]. Evaluation of the health extension programme in Ethiopia has indicated some notable successes, including a higher proportion of children vaccinated against communicable diseases and an increase in the use of bed nets to prevent malaria [25]. However, HEWs have not been involved in the care of children with mental health problems in Ethiopia. Additionally, the initial HEW training programme did not include any training in mental health. To address these concerns, in 2011 the Federal Ministry of Health (FMOH) of Ethiopia, in partnership with the Open University UK, developed a new training programme to upgrade HEWs (to level 4 or diploma grade), which included training in mental health through the Health Education and Training (HEAT) programme. The HEAT curriculum covers key topics in child and maternal health, family planning and sexual health, environmental hygiene, communicable and non-communicable diseases. HEAT is delivered primarily through face-to-face teaching (lecture methods) supported by printed training modules for the HEWs. The mental health section comprises ten study sessions, equivalent to two weeks of fulltime study. One study session, (i.e. equivalent to one day study time) focuses on child mental health, covering topics such as the importance of healthy development, enuresis and intellectual disability, with a brief mention of autism. (The HEAT study materials are available in full as open educational resources from the HEAT (Health Education and Training) website at http://www.open.ac.uk/africa/heat).

When this study was initiated, about 1300 HEWs were trained in the HEAT modules in a pilot project across the country and currently 12,700 have completed the HEAT training and have been upgraded to Level-4 (Personal Communication, Federal Ministry of Health, 2016). However, competency needs and perspectives of HEWs about the integration of child mental health care into their routine practice have not previously been explored. Therefore this study examined training needs and perspectives of HEWs, including barriers and facilitators, in relation to integrating child mental health care into community-based PHC services in Ethiopia.

Methods

Setting

The study was conducted in the Southern Nations, Nationalities, and Peoples' Region (SNNPR) of Ethiopia. The SNNPR was chosen because of existing research infrastructure of Addis Ababa University in the region. From the Ethiopian census of 2007 [26], SNNPR has an estimated population of around 15 million and hosts over half of the ethnic diversity of Ethiopia. The region is predominantly rural; nearly 90% of inhabitants reside in rural areas. The official language of SNNPR is Amharic. Between 2003 and 2009, SNNPR trained 7492 rural HEWs [27]. In 2011, 208 HEWs from SNNPR enrolled in the HEAT training, of which 204 successfully completed the training.

Study design

A mixed methods approach, consisting of a cross-sectional survey and qualitative study, was employed. The qualitative study was included to obtain a more in-depth understanding of the experiences and perspectives of HEWs.

Participants and sampling

A total of 204 HEWs from the Southern Nations, Nationalities, and Peoples' Region (SNNPR) were trained in HEAT in 2011. There are four HEAT training centers in the region. Our study sample was recruited from the 116 HEWs trained in the Hawassa and Hossana facilities. All HEWs are female due to the policy of the Federal Ministry of Health of Ethiopia.

The HEAT trained HEWs were identified via the regional health bureau and were informed in advance about the study. If the HEW agreed to participate in the study, the HEWs were invited to the nearest College of Health Sciences (Hawasa and Hosana) to carry out the assessments centrally. All 116 HEAT trained HEWs were invited and 104 (89.7%) attended. All of those who attended gave informed consent to participate.

For the qualitative study, in-depth interviews were conducted with 11 HEAT-trained HEWs selected purposively on the basis of the administrative zone within which they worked. This "zone-based" selection was to ensure diversity of localities of origin in order to capture the broader range of experiences.

Measures

Both structured and open-ended questions were used. The structured questionnaire comprised two parts: sociodemographic characteristics (age, religion, educational status and work experience) and learning needs and experience. The learning needs and experience questionnaire gauged the interest of participants on attending the training on child mental health and on their perspectives regarding the quality of training resources and the importance of the topic. This section also included questions on whether or not the participants had made use of the training resources in their practice, for example, whether they had organized a mental health awareness meeting in the community to discuss about mental health problems. The open-ended questionnaire explored whether the study material helped in their daily practice, and solicited suggestions on improving the study material, including what the HEWs thought would be useful to include in the training. For in-depth interviews, a topic guide was prepared to guide the discussion with HEWs. The in-depth interviews expanded on the quantitative survey and probed specifically around child developmental disorders, autism and intellectual disability (ID); a specific focus on developmental disorders was chosen because these conditions are explicitly included in WHO's mhGAP programme as a priority condition for action [28]. The in-depth interviews explored the following areas: training needs and the perceived importance of the training; perspectives on the modules and training; barriers and facilitators to developing child mental health services; and suggestions for improvement of the training materials.

Data collection

The questionnaires were prepared in English, translated into Amharic and then back-translated into English to ensure consistency. Amharic is the official language of Ethiopia and the region. The instruments were pre-tested in a small group of HEWs. A final version of the questionnaire was established following feedback from the pretest. All data collectors were women who had completed secondary school and had extensive experience in data collection. The data collectors were thus of the same gender and of similar socio-economic status as the participants, limiting possible bias in their responses. The data collectors were trained to administer the questionnaire through face-to-face interviews. Training was given over five days to ensure that the data collectors were familiar with the data collection procedures, the questionnaire, information sheets and consent forms.

The in-depth interviews were conducted by DT in private in Amharic. With the agreement of participants, the interviews were audio-recorded. Electronic Amharic transcripts were produced and these were translated into English.

Data analysis

The quantitative data were analysed using SPSS version 20 (IBM SPSS Statistics 20). The analyses were primarily descriptive. Categorical values were summarized in absolute numbers, and percentages were calculated to one decimal place. Mean and standard deviation was employed for continuous variables. For in-depth interview data, analyses utilized the interview transcripts, interview summaries and the field notes. The English transcripts were analyzed using OpenCode 3.6 qualitative data analysis software [29]. A framework analysis was used [30], a common approach in qualitative research that employs several stages: familiarization, identifying the thematic framework, indexing, charting and interpretation. The first author coded all of the transcripts and one of the authors (AF) read and gave feedback on the translations, and coding process for possible themes/codes and quotes. An initial list of codes and themes was developed and reviewed and then refined after further re-reading. Illustrative quotes were selected for the resulting themes. The quotes were sufficiently in-depth to allow readers to understand the context of the responses. Finally, the analyzed qualitative data were triangulated together with the quantitative findings.

Results

Socio-demographic characteristics of respondents

A total of 104 HEAT trained HEWs were included in the analyses. All HEWs were female and their mean age was 25.8 years (SD 3.5). Most of the participants were either protestant (67.3%; n = 70) or Orthodox christian (19.2%; n = 20) in religion (Table 1). On average the HEWs had been employed for about 76 months at the time of the study. All were surveyed about 4 months after their HEAT training. That is, most HEWs had worked for a couple of years as HEW prior to taking up the HEAT upgrading training. All HEWs had returned to their health post after completion of the HEAT training, to continue their work, now as a higher qualified health worker.

Learning needs of HEWs

All HEWs surveyed considered the topic of child mental health to be important or very important (n = 104). Most of the HEAT-trained HEWs (88.5%; n = 93) reported that they were interested in the study modules focusing on childhood mental health problems (Table 2). The perceived quality of all mental health study texts (i.e., not only child mental health) was average or above average (76.9%, n = 80) with 23.1%, n = 24 perceiving it to be below average. Nineteen HEWs (18.3%) did not have access to the study materials. Most of these (53%) who did not have access to the study materials rated the materials as below average while only 16% of those who had the study materials rated the materials as below average.

The in-depth interviews largely reinforced the above views. However, some participants expressed that important concepts about child mental health problems, especially on child developmental disorders, were not covered adequately.

Table 1 Background characteristics of participating health extension workers (n = 104)

Socio-demographic characteristics	Frequency	Percentage
Religious affiliation		
Muslim	12	11.6
Orthodox christian	20	19.2
Catholic	2	1.9
Protestant	70	67.3
Highest grade you completed at school		
Grade 10	69	66.3
Grade 12	35	33.7
	Mean (standard deviation)	
Age in years	25.8 ± 3.5	
Overall work experience as HEW (months)	75.7 ± 13.6	
Work experience in current post (months)	69.7 ± 20.1	

"[…] I think there is nothing missing from the contents of the modules on adult mental disorders. However, training on mental health needs of children lacked many things. The module […] covered very little on child developmental disorders and autism. It would be better to include the symptoms of developmental disorders, including autism, and details on how to make diagnosis, identify causes and provide treatment. The other problem was that the original teaching materials [on mental health] were not available and we had to make copies [for our use]." (HEW 5).

Regarding the importance of the subject of child mental health problems, one participant stated:

"[…] Generally the training was very important; I gained knowledge about developmental disorders… When I compare myself from previous, I learned many things […] after training I learned how to treat, identify and manage childhood mental problems." (HEW 1).

Experience and role of HEWs

Nearly half of the trained HEWs (46.1%; n = 48) reported that they made use of the mental health training modules, which included the child mental health section, once or twice a week (Table 3). The in-depth interviews revealed some challenges in their experience of using the training materials.

"[…] The instruction in the English language was difficult to understand […] In addition, as this was a new course, my limited previous training and knowledge about child developmental disorder made it very difficult to understand child mental disorders." (HEW 1).

The other participants also emphasized the problem:

"There is a language problem […]. Even the few things we understood about adult mental problems was because the instructor translated his lecture into Amharic [the local language] during his teaching. The child mental health session was not clear and has only limited content with very little [information] on autism. So we need to learn in detail about each kind of the disorder, using simple language." (HEW 2).

When the respondents were asked about how the training and training materials helped in their daily work, most reported benefits as improvement in knowledge and awareness, case identification and provision of service (Table 3). Qualitative study participants confirmed

Table 2 Attitudes of Health extension workers towards training and training materials

Questionnaire items	Frequency	Percentage
Access to training materials		
Yes	85	81.7
No	19	18.3
Opinion of quality of study material		
Extremely poor	14	13.5
Below average	10	9.6
Average	33	31.7
Above average	17	16.4
Excellent	30	28.8
Overall, did you find the mental health and childhood problems study text interesting to study?		
Not at all interested	5	4.8
Of little interest	7	6.7
Moderately interesting	35	33.7
Interesting	18	17.3
Very interesting	39	37.5
Do you feel that the topic of childhood behavioural and developmental problems is important for a HEW?		
Not at all important	0	0
Of little importance	0	0
Moderately important	0	0
Important	4	3.8
Very important	100	96.2

Table 3 Experience of health extension workers in utilization of the training materials

Questionnaire items	Frequency	Percentage
Do you use any of the training provided in the mental health and childhood problems study material in your work?		
No, never	14	13.5
Yes, but only rarely (once or twice a year)	19	18.3
Yes, sometimes (about once a month)	23	22.1
Yes, often (about once a week)	20	19.2
Yes, very often (more than once a week)	28	26.9
If Yes, how did the training help you in your daily work?[a]		
Increasing knowledge and awareness	52	50.0
Improve the service	22	21.2
Identification of the case	14	13.5
Motivated me to do and read the materials	8	7.7
Counseling	8	7.7
Referral	6	5.8
Have you organized a mental health awareness meeting in your community?		
No, never	67	64.4
Yes, but only once	26	25.0
Yes, two or more meeting	11	10.6

[a] Respondents could provide multiple answers

similar benefits of training: as a gain in knowledge, skills, a positive attitude and confidence. For example, one participant stated:

> *"... After training I gained knowledge, [was] able to detect child mental disorders, including autism. This motivated me to give health education to raise awareness in the community about misconceptions, [for example] not to hide a child with developmental disorder, negative attitudes, and stigma and was able to refer cases to the hospital and provide advice on care and support." (HEW 9).*

On the other hand, many of the participants reported having poor knowledge and said that they were unable to distinguish autism from the other types of child mental disorders. They also lacked the skills and confidence to identify, treat and refer child mental health problems. Most also said they were fearful and embarrassed about approaching and helping families with an affected child and that their negative attitude might have been a barrier towards providing support to children with development problems.

> *"[...] the other problems that affected me doing this work were my own fear and misperception that the family may not accept my advice and my belief that such cases could not be cured or have treatment." (HEW 3).*

> *"[...] my negative attitude and misperception towards improvement of children with developmental disorder is a problem towards helping a child with mental problems. (HEW 9).*

Even though the HEWs had only returned to their community 4 months prior to the survey, about one-third (35.6%, n = 37) of HEWs reported that they had organized a mental health awareness meeting in their community since (Table 3). However, other participants reported little activity at their work place because of their poor competency and health institution constraints such as lack of knowledge and skill of PHC workers at health centers, large coverage area and overload of work, problem of transport, lack of supportive supervision and coordination. The activities the HEWs reported that they had performed included identification of cases, counselling, awareness raising, organizing community meetings, provision of direct services, referring and follow up and monitoring during home visits.

Rationale for training

All HEWs reported a high level of need for training on identification and treatment of child mental health problems. Most of surveyed HEWs said that child mental

problems were very common in the community and had a large impact on the family and individual. The impacts were mostly perceived to be related to financial, social and health related burdens. The social burden mentioned by the participants were related to the child's behavioural difficulties, carers being unable to work and being limited in their ability to participate in social activities because of needing to be the carer, negative attitudes from the community and stigma. Economic burden on families, such as the cost of transport and treatment was also reported by HEWs. Most of the HEWs interviewed in-depth thought that the caregivers' burdens were aggravated by the lack of availability of treatment at PHC and poor awareness, negative attitudes and stigma from the community about the condition.

> *"[…] there are many children with developmental disorder in the community; for example in my kebele [administrative sub-district, each consisting of about 5000 people] I have identified four cases, all of the children do not speak even when they are hungry […]. I gave advice on hygiene and appropriate diet to the families of children with such problems […]."(HEW 8).*

> *"[…] Financial problems of the family to access treatment for their child with a developmental disorder after referral was a challenge that hindered my day to day work […] other problems are lack of available services and resources….for example special schools to educate these children….and lack of trained health personnel to help children and their families at health centers [the primary care facility to which HEWs would refer] in rural area. These are the most important problems. So treatment, care and support need to be found and improved at the health center level […]." (HEW 4).*

> *"[…] the other problem was negative attitudes and misperceptions in the community and family about treatment and the cause [of their child's condition] during counselling and awareness raising … i.e. the belief of the community that these kinds of conditions do not need modern treatment and can be transmitted to others. The belief is that the cause is a punishment from God, and that intervention is only possible through traditional or religious treatments such as praying, holy water, spiritual beliefs etc. […]." (HEW 5).*

The HEWs also reported a need for further training due to their low level of baseline competency in the identification of affected children, to provide interventions and awareness of referral services. They recognized a need to improve motivation across all HEWs to provide this service. They also recognized a need to improve the quality of care and safety of families and their affected child. The majority of HEWs reported that, as they were already delivering different packages of home-based care for mothers and children, they would easily be able to identify and treat the children if they acquired adequate knowledge and skills.

HEWs reported the need for expanded in-service training. When asked to suggest specific content to be included in future training on mental health and childhood problems, the most commonly reported training need was for detailed, clear and separate training on child developmental disorders (74.1%, n = 77) (Table 4). Almost all of the in-depth interview participants wanted in-service training, especially in the identification, causes, prevention and treatment of child mental health problems, including developmental disorders.

The most important unmet need on methods of training was preparation of a detailed, clear and separate module on child mental health and developmental disorders (74.0%, n = 77) and practical training mostly on how to give support, including first aid to families with mental health needs (21.2%, n = 22) (Table 4). In-depth interviews also indicated similar training needs. One HEW said;

> *"We are giving service at the grass root level and in the community, so we need to be up to date with the new information and advance in our knowledge and skill to ensure detection, treatment and referral. Then we can share and provide an appropriate service for model family and community/family [1 out of 6 families are trained as 'model' families for*

Table 4 Self-reported training needs of health extension workers

Health extension worker recommendations	Frequency	Percentage
Suggested area to be included in mental health and childhood problems study text[a]		
Detailed, clear and separate session	77	74.1
Signs, symptoms and cause or detail on identification	20	19.2
Management and treatment	16	15.4
More practical part i.e. about first aid	11	10.6
Suggestions on how study text can be improved[a]		
Detailed, clear and separate module	77	74.0
Practical training	22	21.2
Simple Amharic	7	6.7
Receiving module on time	8	7.7
Adequate time for training	6	5.8

[a] Respondents could provide multiple answers

health promotion and education activities] but we didn't get this opportunity. [...] my suggestions as a means of improvements are refresher courses (in-service training) [...] about developmental disorders." (HEW 7).

Barriers to integration of child mental health care

Many barriers were reported to affect the integration of child mental health care into existing routines. The identified barriers were at the level of the individual, community and institution.

The barriers at the level of the HEW included poor knowledge and skills, negative attitudes and stigma and demotivation. The barriers at the community level were misconceptions, negative attitudes, stigma and discrimination. This is stated by one participant as quoted below;

"[...] lack of adequate knowledge and skill on child developmental disorders also minimize my confidence in helping families. Negative attitude and misperception held by the community and families also decrease our motivation to help [...]." (HEW 5).

Two HEWs described how disease attributions may be barriers encountered within a family:

I have got one child in our survey; he does not talk. His parents were hiding information about him. They thought that this type of disease is cured through traditional or spiritual means. They said [his illness was] due to spirit possession-likift-because someone had given him some potion. When I saw the child he was very pale and [...] chained. Then I started to discuss how this child should be treated [...] but parents said if this child got medical treatment he may die; instead traditional treatment like slaughtering [an animal] and praying were their preferred treatment. Finally we planned another appointment for further intervention and discussion about referral of the child." [HEW 2].

"[...] at the beginning he (father) became resistant because of his strong belief that [the child's] condition was not curable through modern treatment because it was the result of punishment from God and that this child could only be treated by holy water." [HEW 3].

In addition, low expectation of community and family of input from HEWs, and lack of appreciation from the community leading to demotivation of HEWs, were also mentioned as barriers.

Institutional barriers such as constraints of resources, including lack of trained health professionals at health centers, lack of services and facilities and financial problems for transport, treatment and other costs, were common barriers mentioned by HEWs. Minimal attention by stakeholders or government bodies, lack of supportive supervision, coordination and collaborative work were also mentioned as constraints. The other barriers for integration of the mental health service into routine practice were insufficient training due to inadequate time allocation, content, methods and scope of training, minimal attention on mental health by tutors, inaccessibility of the module and other reference materials, and heavy work load.

"[...] lack of health services (treatment, care and support) and special schools to help these children and their families in the rural areas are the most important barriers. Constraints of time because of overload of work are also another barrier. So care and support including treatment need to be improved." (HEW 4).

Other HEWs also explained that when there are no skilled professionals to provide care at the health centers, or a family cannot afford to take their child to a health centre, this limited the acceptability of the care they can provide.

"Lack of skilled health professionals to help children at the health center after referral and financial problems of parents to take up referral also reduces our acceptability." (HEW 5).

"Ignorance of the community and lack of attention from the government are also some of the problems that needed to be solved." (HEW 9).

Facilitating factors to overcome barriers for integrating child mental health care

Most respondents considered child mental health problems as important and had a positive attitude and interest toward training and providing care for children with mental health problems. The other facilitating factors reported were availability and the use of reference materials provided as part of the HEAT training. High motivation and willingness of HEWs to apply and maintain an effort in their task, positive attitude and suggestion of HEWs to integrate the child mental health care into routine general health service were also mentioned as facilitating factors for integrating child mental health service. Some HEWs were identifying child mental problems and getting involved in the actual service delivery of child mental health care. One participant explained the benefits as:

"There is a change in my knowledge and skill and the training helped me to plan and to survey for detection or diagnosis of cases. It also helped me in mobilizing the local community; this supports the detection of cases because people know where children with mental problems including autism are found i.e. they [community] can easily identify in which house a child with autism is found." (HEW 2).

The organizational structure of the district and the work of HEWs with families was considered as an important facilitator.

"[…] Working on child mental health problems is not problematic or a challenge, because our work is mostly with mothers; so we can easily access children with no [extra work] overload. This work is very important because children are the future generation of the country." (HEW 7).

HEWs also suggested many facilitators to overcome barriers for integrating child mental health care. The suggested facilitators for addressing the barriers in performing tasks and integrating child mental health care services were in-service training for HEWs and general health staff and awareness raising programmes using mass media for those in positions of authority and stakeholders. Expanding availability of services in the health sector, school setting and other settings were also suggested for the improvement of care for the child and family. Facilitating referral linkage, coordination of activity, integration and collaboration of work and continuous supportive supervision were also suggested. The other most important suggestions to address barriers were practical exposure to mental health problems during training and improvement of the contents, methods and scope of training. Concerning this issue, one of the HEWs said;

"Accessibility and availability of information and services for children, their family and the community about developmental disorders and child mental health care are mandatory. In addition in-service training for all HEWs that did not receive HEAT training should be given i.e. every HEW should get the chance of learning how to detect, treat and help children with developmental disorders, their families and the community…. my friend (HEW in the same kebele) also needs to get this training [HEAT training] to improve treatment, care and support." [HEW 4].

Another participant said "[…] In order to increase awareness-raising, motivation and advocacy on child mental problems, attention needs to be given to integrated work, involvement of all important stakeholders e.g. administrators, religious leaders and other stakeholders. So help and integration from other stakeholders are mandatory to bring change, to solve the problems of the individual, their family and community and prevent further burden." (HEW 5).

Discussion

In this mixed methods study of rural community-based HEWs from Ethiopia with very limited training in the mental health needs of children, the burden of mental disorders among children in the community was considered high. We found a high level of interest and motivation to learn about child mental health and developmental needs of children and to provide services. HEWs reported that, through the training, they would be able to improve quality of care and address the issue of the widespread stigma and discrimination of mental health and developmental problems. Integration of mental health care of children into routine community based primary care practice was acceptable to the HEWs. In addition, several facilitators and barriers for integrating child mental health care were mentioned by HEWs.

Learning needs and experience

The positive attitudes of HEWs towards training about mental health needs of children and the HEAT study resources may facilitate the implementation and integration of mental health care of children into primary health care. This is consistent with previous findings in LMICs among community health workers that indicated acceptability of training [6, 14] and a positive impact of training on improving knowledge, skills, satisfaction, confidence, motivation and actual performance [14, 17–19, 31–33]. Motivation of health workers is known to be an important factor in the successful implementation of services at the primary health care level [14].

One of the encouraging findings of this study is that even though most HEWs had only recently returned to their community to work as HEW after completing their upgrading training, nearly half of the trained HEWs reported that they had been using the mental health training materials regularly in their practice. This has resulted in self-reported improvements in knowledge, skills and attitudes consistent with reports of improved knowledge, competence and performance among HEWs with the use of guidelines and protocols [14, 31–33]. Interventions to encourage the consistent use of the training materials or improving their utility by developing simpler pocket guides or flow charts may be an important next step. A third (35.6%) of the participants had organized a mental health awareness-raising meeting within four months of training. Given the short time

following training to organize mental health awareness meetings and the competing responsibilities HEWs have, organizing these meetings appear to be an important achievement induced by the training.

Rationale for training need

HEWs considered mental health needs among children to be common and this was their primary justification for perceiving that they needed training. They expressed the view that training of frontline HEWs was important in addressing the treatment gap in children. Such rationales have also been identified elsewhere [34, 35] and speak to the need to include public health arguments about the population level benefits of community interventions. The related issues of family needs were also considered to be important reasons for the training. Childhood health needs are reflections of the broader family need and may impact seriously on the broader family context. Again this is also an important consideration in developing training resources for community providers who interact with families as part of their routine practice. The need for improving knowledge and confidence in case detection, and quality care provision were also mentioned as important rationales for training, consistent with other reports from Ethiopia [23–25, 36, 37] and elsewhere [14, 38].

Barriers for integration of child mental health care service

In our study poor knowledge and skill were the frequently endorsed barriers for integration of child mental health care into primary care. The majority of the study participants reported that they did not know how to detect, support and prevent child mental health problems as a result of poor competence. This finding is consistent with other reports among HEWs [23, 24] in Ethiopia and community health workers [14, 16] in other LMICs. The HEAT curriculum studied by the HEWs only included one day of study on child mental health and developmental disorders; our participants' responses indicate the need for further training on this topic. The other barriers were negative attitudes and stigma [37, 39]. Compared to other aspects of their work, the high challenge of child mental health care for HEWs in our study may be related to the low baseline knowledge, the lack of referral services and stigma. Moreover, the broader lack of research and policy guidance may play a part. For example child mental disorders were not included in the implementation of the mental health Gap Action Programme in Ethiopia or other implementation studies, such as the programme for improving mental health care [37, 39]. It is important to develop research evidence such as presented here to support the scale up of mental health care and also address negative attitudes and stigma among HEWs and families [17, 19].

Another barrier mentioned in our study was demotivation as a result of low expectations of the community and other stakeholders from the HEWs. Similarly, unrealistic expectations, for example, the vast majority expecting cure [39], poor planning and underestimation of the effort required, were causes of numerous failures of programmes and damaged the credibility of providers [19, 40]. Institutional level factors, including lack of availability and accessibility of services and facilities, and lack of resources such as time, trained health professionals, and lack of supervision and coordination were also reported to be barriers for integration of the service, in keeping with findings from programmes for other disorders [6, 14, 24, 40].

Facilitating factors or opportunities for integration of service delivery

The recognition of child mental health problems as important and the overall positive rating of the training materials may facilitate integration of child mental health care into routine primary care. Such factors are identified as important enablers of integration and sustainability of programmes implemented by community health workers [6, 14, 18]. The use of the reference resources provided by the training programme and engagement in organization of community awareness programmes are potential enablers, as were identified elsewhere [6, 14, 33, 41, 42]. However, nearly a fifth of the trainees did not have access to the training materials and this problem was augmented by the language difficulty. This speaks to the need for careful adaptation and piloting of such resources before they become more widely available, as well as to ensure availability of resources to all students after roll-out.

The HEWs reported that their training had improved their knowledge, skill and confidence to detect mental disorders in children and to help family members of children with developmental disorders. This confidence, coupled with the high motivation and willingness of HEWs to apply their training, would be important facilitators of integration into routine practice [6, 42]. The new role of supporting child mental health care is also consistent with the role HEWs felt they had and this perception would also be an important facilitator [14, 35, 43].

Limitations and strengths of the study

It must be noted that the findings of this study represent only the perceptions of HEWs. We did not study the reflections of children with developmental disorders or their families and other stakeholders. The circumscribed geographic area where the study was conducted also affects generalizability of the findings, although the addition of the qualitative study enhances the relevance of our findings. The HEW program is relatively new to the

Ethiopian health care delivery system, which limits the comparisons of the current findings with similar studies conducted earlier. However, the study is the first study in Ethiopia among HEWs on child mental health training and provides relevant information in an area of public health challenge of which very little is known, not just in Ethiopia, but in Africa more widely [44].

Conclusions

Although the HEAT training on child mental health was brief, it appears to have had an important impact in motivating community health workers and in providing services for children with mental health needs and their family. If the key barriers to service provision are addressed and supported by policy guidance, HEWs may contribute substantially in addressing the treatment gap for children with mental health needs.

Abbreviations

HEWs: health extension workers; HEAT: health Education and Training (HEAT); HIC: high-income countries; LMICs: low- and middle-income countries; PHC: primary health care; WHO: World Health Organization.

Authors' contributions

DT, CH, RH, and AF all contributed to the study design, DT conducted the study. DT, CH, RH and AF analysed the data. DT wrote the first draft of the manuscript. All authors contributed to interpretation of the study findings. All authors reviewed the final manuscript prior to submission. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

Availability of data and supporting materials

The data are being used for a Ph.D. student for their thesis and are not, therefore, available at the present time to the general public. The data may be requested from the corresponding author for verification of the analyses in this paper.

Ethical approval and consent to participate

Ethical approval was obtained from the Institutional Review Board of the College of Health Sciences, Addis Ababa University and The Open University (UK). All study participants were informed about the purpose of the study and written informed consent was secured from all participants prior to the start of data collection. All electronic data resulting from the project were stored on a secure computer and the survey results were not directly linked to contact details. Participants were provided with refreshments after the in-depth interview.

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Annex 1.3. Tilahun D, Fekadu A, Araya M, Roth I, Davey B, Hanlon C, Hoekstra RA. **Ethiopian community health workers' beliefs and attitudes towards children with autism: impact of a brief training**. (*Manuscript, Autism)(**unpublished**)*

Ethiopian community health workers' beliefs and attitudes towards children with autism: impact of a brief training intervention

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Abstract

There is a severe shortage of services for children with autism in Ethiopia; access to services is further impeded by negative beliefs and stigmatising attitudes towards affected children and their families. To increase access to services, care provision is decentralised through task-shifted care by community health extension workers (HEWs). This study aimed to examine the impact of a brief training (Health Education and Training; HEAT) for Ethiopian rural HEWs and comprised three groups: i) HEWs who completed a basic mental health training module (HEAT group, N=104); ii) HEWs who received enhanced training, comprising basic HEAT as well as video-based training on developmental disorders and a mental health pocket guide (HEAT+ group, N=97); iii) HEWs untrained in mental health (N=108). All participants completed a questionnaire assessing beliefs and social distance towards children with autism. Both the HEAT and HEAT+ group showed fewer negative beliefs and decreased social distance towards children with autism compared to the untrained HEW group, with the HEAT+ group outperforming the HEAT group. However, HEAT+ trained HEWs were less likely to have positive beliefs about children with autism than untrained HEWs. These findings have relevance for task-sharing and scale up of autism services in low-resource settings worldwide.

Keywords: Autism Spectrum Disorder; Developmental disabilities; Community Health Workers; Developing Countries; Ethiopia; Stigma; Attitude

Autism and other developmental disorders (DD) are increasingly recognised as conditions associated with long-term burden, disability and cost, requiring global action (Kieling et al., 2011; Patel et al., 2013; WHO, 2001). The global prevalence of autism is estimated to be around 0.6% (Elsabbagh et al., 2012). The prevalence of autism in sub-Sahara Africa is unknown (Elsabbagh et al., 2012), but prevalence studies of general mental health problems and intellectual disability in low and middle income countries (LMIC) suggest that these problems are at least as prevalent as in high-income countries (Maulik et al., 2011; WHO, 2008). In most LMIC mental health and developmental problems are aggravated by a severe shortage in mental health care provision, resulting in large treatment gaps (Saxena et al., 2007).

Ethiopia is a country located in the horn of Africa with a population of almost 100 million people, half of whom are children. Our recent situational analysis of autism services in Ethiopia (Tekola et al., 2016) showed that diagnostic and educational services for children with autism are largely confined to Ethiopia's capital, Addis Ababa, and therefore unavailable to the majority (85%) of families who live rurally. There are only two child psychiatrists working in Ethiopia; the two schools for children with autism in Addis Ababa are both highly oversubscribed with long waiting lists. The identification, care and treatment of children with autism are further hindered by stigma, negative stereotypes and misconceptions about the causes of DD and child mental illness (Abera et al., 2015; Tilahun et al., 2016). Supernatural explanatory models, for example, attributing a child's problems to a curse or spirit possession, are common, both in caregivers of children with DD (Tilahun et al., 2016) and in parents of general population school children (Abera et al., 2015). Ethiopian caregivers of children with DD report high levels of stigma; higher experienced stigma was associated with seeking help from traditional institutions

and providing a supernatural explanation for their child's condition (Tilahun et al., 2016). Supernatural explanatory models of mental illness and negative attitudes towards people with mental health problems are also common among nursing staff in Ethiopia (Deribew and Tesfaye, 2005; Abera et al., 2014). Examining beliefs regarding autism among health professionals, studies in Kenya (Gona et al., 2015) and Nigeria (Bakare et al., 2009) indicate that similar negative beliefs and misconceptions about the causes of autism are common in other sub-Saharan African countries. People with religious or supernatural beliefs about causation are likely to have less tolerant attitudes towards people with mental health or developmental problems (Gureje et al., 2006). These views and beliefs may, therefore, hamper identification and successful community rehabilitation of children with autism. Consequently it is likely that the adult community also includes many individuals whose autism goes without recognition or support.

One of the most promising strategies to address the treatment gap for children with autism and other DD is decentralisation of mental health care provision through task-shifted or task-shared care by non-specialists (Saraceno et al., 2007; Patel et al., 2013). Community health workers, referred to as health extension workers (HEWs) in the Ethiopian health system, have a great potential to be involved in decentralised care provision. To improve the general health care facilities for people living in rural areas, Ethiopia launched a community-based health services extension programme in 2003. Since then 38,000 HEWs completed a one-year training course before starting work in rural Ethiopia. Every rural *kebele* (the smallest administrative unit in Ethiopia, comprising about 5000 inhabitants, half of whom are children) is assigned two HEWs. The HEWs deliver primary community healthcare services consisting of health promotion and prevention packages at their health post. In addition, HEWs are actively

engaged in outreach services by visiting the houses of people in their community and training model families and community volunteers (Koblinsky et al., 2010). Evaluation of the initial Ethiopian health services extension programme indicated some notable successes, including a significantly higher proportion of children vaccinated against communicable diseases and an increase in the use of bed nets to prevent malaria (Assefa et al., 2009). However, there was little impact of the programme in other health areas. More importantly in the context of autism, the initial programme did not include any training on mental health or DD.

To address these concerns, the Federal Ministry of Health of Ethiopia worked with The Open University (UK) to develop the Health Education and Training programme (HEAT; http://www.open.ac.uk/africa/heat/) to upgrade the training of existing HEWs. The HEAT curriculum covers topics in child and maternal health, family planning and sexual health, environmental hygiene, communicable and non-communicable diseases. Ten study sessions specifically concern mental health, though child mental health and developmental problems receive only limited attention, with virtually no content on autism spectrum disorders.

About 1,300 HEWs were trained using the HEAT modules in a pilot project across the country at the launch of HEAT in 2012; since then, over 12,700 have completed the upgrading training using HEAT study materials (Personal Communication, Federal Ministry of Health, 2016). Following their HEAT training, we examined the experiences and remaining training needs of 104 HEWs who had just completed the HEAT pilot (Tilahun et al., 2017). The majority of surveyed HEWs were satisfied with the HEAT training materials on mental health and over two third of HEWs indicated they used these study materials at least once a month in their job.

However, 74% of the HEWs also indicated they would benefit from additional training on child mental health and DD. Qualitative interviews with a subsample of HEWs indicated HEWs feel they lack knowledge and skills to adequately support children with DD in their community. In response to these findings, we developed an enhanced version of the HEAT mental health training, called HEAT+. This covered a range of adult and child mental health problems, and included training materials specifically focussing on autism and intellectual disability in children. In the HEAT+ research project we surveyed the experience, knowledge and attitudes of HEWs who were trained using HEAT or HEAT+, and compared their experience, knowledge and skills with HEWs not yet trained in mental health or DD. The aim of this study was therefore to evaluate the impact of the basic and enhanced Health Education and Training (HEAT and HEAT+) materials on the beliefs and attitudes towards children with autism in rural HEWs in Ethiopia.

Methods

Study setting

The study was conducted in the Southern Nations, Nationalities, and Peoples' Region (SNNPR), one of the eleven federal administrative regions of Ethiopia. From the Ethiopian 2007 census (Ethiopian Central Statistical Agency, 2012), SNNPR has an estimated population of around fifteen million people, comprising 45 ethnic groups. The region is predominantly rural; nearly 90% of inhabitants reside in rural areas. Upon the launch of the community-based health services extension programme, 7492 rural HEWs were trained in SNNPR between 2003 and 2009 (WHO, 2010). In 2011, the first cohort of 208 HEWs from SNNPR enrolled in the HEAT training, of

which 204 successfully completed the training. In 2013 a new cohort were trained using the enhanced (HEAT+) mental health training materials.

Participants

This cross-sectional study comprised three groups: i) HEWs who completed the original HEAT mental health module (HEAT group; N=104); ii) HEWs trained using the enhanced HEAT mental health module (HEAT+ group; N=97); iii) practicing HEWs not yet enrolled in the upgrading programme, who had not yet received any mental health training (untrained group; N=108). The study participants in the HEAT and HEAT+ groups had all received their training in the study sites Hawassa or Hosanna, two of the four available training facilities in SNNPR at the time of the study. The HEAT group had completed their training on average 16 months prior to the data collection and had since returned to their local community to work. All HEAT trained HEWs who studied in Hosanna and Hawassa (N=116) were invited to take part in this study; complete data are available for 104 HEWs (participation rate 89.7%). HEWs enrolled in the HEAT+ training had completed the HEAT+ mental health module on average 4 months prior, but were still completing other modules of their upgrading training and had thus not yet returned to their local community. Out of the 104 HEAT+ trained HEWs invited to take part, 97 participated (93.3%). Lastly, a total of 116 HEWs not yet trained in HEAT or HEAT+ were invited to take part, of which108 participated (93.1%). All participating HEWs were female, following the policy of the Federal Ministry of Health of Ethiopia. Each HEW works alongside one HEW colleague in her local community. Working alongside a colleague who had already completed mental health training may affect a HEWs' knowledge and attitudes about autism; we

therefore asked whether a HEW worked alongside a trained or untrained colleague. This information and further demographic data is provided in Table 1.

Training

Two types of educational interventions were provided as briefly described above: i) the basic mental health module (HEAT), and ii) the enhanced HEAT mental health module (HEAT+) of the upgrading programme for Ethiopia's HEWs. The basic HEAT mental health training materials comprise ten sessions, equivalent to two weeks of fulltime study, and include a focus on mental health management, assessment, and mental illness prevention strategies. One session focuses on child development and child mental health, including a discussion of developmental problems. Autism is described only very briefly, in two sentences. The HEAT training was provided through class teaching using printed module materials written in English, following the language policy of the Federal Ministry of Education; most students had access to their personal copy of the training materials (Tilahun et al., 2017).

The enhanced HEAT training comprised the basic HEAT materials, as well as a DVD and a mental health 'pocket guide'. The DVD includes five short video scenarios modelling an HEW interviewing mothers of children with autism or intellectual disability, demonstrating skills in early detection, supportive counselling and problem solving. The mental health pocket guide provides a brief introduction to mental health with a main focus on detection, mental health first aid and providing support to affected families. The pocket guide includes a dedicated child section, with substantially more information on autism and intellectual disability than provided in the basic HEAT materials. The pocket guide was prepared in English and subsequently

translated to Ethiopia's official language Amharic. The scripts for the video scenarios were written in English, and then translated to and filmed in Amharic. In addition to the basic HEAT materials, HEWs in the HEAT+ group viewed the training videos as part of their in-class education, and received a personal copy of the pocket guide. The tutors teaching the enhanced HEAT training were given copies of all HEAT+ materials a month before they delivered the training to students, allowing them to prepare their lessons.

Both the basic HEAT materials and the HEAT+ materials are open educational resources, freely available online on the Open University's HEAT website (quick link: www.tinyurl.com/heatplus). All HEAT and HEAT+ resources were produced by a team of Ethiopian and UK-based experts in mental health and/or pedagogy, ensuring that the materials were culturally and contextually appropriate. The materials use clear learning outcomes directly linked to the key competencies expected of upgraded HEWs (Federal Democratic Republic of Ethiopia, Ministry of Education, 2016).

Measures

All participating HEWs were asked to complete a structured questionnaire, including a case vignette of a child with autism. Following the case vignette, the HEWs were asked various questions related to autism, including their general beliefs about autism and their preferred social distance ((a measure of what level of intimacy and interaction they would accept) from children with autism. These questions were adapted from the World Psychiatric Association's programme to reduce stigma and discrimination because of schizophrenia (Stuart and Arboleda-Florez, 2001). A similar questionnaire has been used to assess attitudes towards mental illness in Nigeria

(Gureje et al., 2005). Adaptation was carried out through expert consensus meetings to make the questions directly relevant to autism and appropriate for the Ethiopian context. The general beliefs questionnaire comprised ten items including questions assessing positive beliefs (e.g. 'children with autism can make their parents proud') as well as negative beliefs (e.g. 'children with autism can bring bad luck on the community'). Items were assessed on a 4-point scale ranging from 0 = 'never' to 3 = 'nearly always'. The social distance questionnaire comprised six items, including e.g. 'would you feel ashamed to be seen out on the street taking care of a child with autism'. Item responses were recorded on a 4-point scale ranging from 0 = 'definitely not' to 3 = 'definitely', with higher scores indicating a greater preferred social distance from children with autism, suggesting stronger stigmatising attitudes. The survey was first piloted in five untrained HEWs in the Butajira area of SNNPR. Based on the pilot final revisions were implemented before the data collection began.

Data collection procedure

The questionnaires were administered to HEWs through a face-to-face interview in Amharic by trained and experienced data collectors. This data collection procedure is commonly used in mental health research in Ethiopia and is appropriate for the cultural setting. Data collectors were all women who completed secondary school (10^{th} grade), and were of similar socio-economic status to the participants to limit social desirability bias in the HEWs' responses. Data collectors were trained over five days; the training focused on good interviewing skills, role plays and observed pilot interviews. The data collection was conducted at the training facilities in Hawassa and Hosanna. All study participants provided their written informed consent prior to participation. Ethical approval was obtained from the Institutional Review Board of Addis Ababa

University's College of Heath Sciences and the Open University's Human Research Ethics Committee.

Data management and analysis

Double data entry using Epidata version 3 (Lauritsen and Bruus, 2003) was employed to reduce the risk of data entry errors. The data were then exported to SPSS version 23 (IBM SPSS Statistics 23) and MPlus version 5.21 (Muthén and Muthén, 2007) for analysis. The factor structure of the adapted questionnaires was assessed in two steps, using exploratory factor analyses (EFA) and confirmatory factor analyses (CFA) in MPlus. The total sample of 309 participants was randomly split in half. Half of the sample was used to conduct the EFA. The factor structure suggested by the EFA was subsequently tested employing CFA using the second half of the sample. Modification indices were used as guidelines to examine whether the fit of the resulting model could be further improved. The overall fit of the models was evaluated using the Comparative Fit Index (CFI) and the Root Mean Square Error of Approximation (RMSEA). A good model fit is indicated by CFI values above 0.90 and RMSEA below 0.08 (Schermelleh-Engel et al., 2003). Once the best fitting models were identified, further analyses were conducted in SPSS. The internal consistency of the resulting scales was estimated using Cronbach's alpha. Non-parametric Kruskal-Wallis test and subsequent Man Whitney U tests were used to examine group differences in a single item. Analyses of covariance were used to examine group differences in quantitative scales. The following four variables were included as covariates in these analyses: HEW's age; length of work experience practising as HEW; educational achievement in high school; and whether the HEW worked alongside a HEAT trained colleague.

Results

Participant characteristics

The sample characteristics for each of the three groups are reported in Table 1. The three groups had a similar distribution of religious affiliations; similar proportions in each group had completed high school to 10^{th} or 12^{th} grade level, and similar proportions worked alongside a HEW colleague who had already completed the upgrading programme. The HEAT group was significantly older and had a significantly longer experience working as an HEW compared to the HEAT+ and untrained groups ($p < .01$). Moreover, the untrained group had a slightly higher average grade in high school than the HEAT trained group ($p < .01$). No other group differences in background characteristics were observed.

Factor analyses

The ten items assessing positive and negative beliefs towards children with autism were examined using EFA. Initial EFA indicated that one item showed little covariance with the other nine items. Item content inspection ('Can improve their language skills with the right help') suggested this item mainly assesses a positive belief in efficacy of an intervention, rather than a positive belief towards children with autism directly. The EFA was re-run including the nine remaining items only. The results indicated a 2-factor structure: one factor comprising four positive belief items, and one factor comprising five items assessing negative beliefs. This 2-factor model was subsequently fitted to the second half of the data. Inspection of the modification indices suggested the fit could be improved by allowing cross-loading of one positive belief item on the negative belief factor. Implementing this modification resulted in a good model fit (CFI= 0.927; RMSEA = 0.064). Next, the six items assessing social distance were

subjected to EFA. The EFA suggested a 1-factor structure; testing this structure using CFA in the second half of the data indicated a very good model fit (CFI= 0.987; RMSEA = 0.063); there were no modification indices above the minimum value. The 4-item positive beliefs scale had moderate internal consistency (Cronbach's $\alpha = 0.54$), acceptable when taking into account the low number of items included. The internal consistency of the 5-item negative beliefs scale ($\alpha = 0.67$) and 6-item social distance scale ($\alpha = 0.72$) were adequate.

Impact of training on beliefs and attitudes

Tables 2 and 3 show the item-by-item responses of the participants in relation to positive (Table 2) and negative (Table 3) beliefs and stereotypes towards children with autism, while Table 4 presents the responses related to preferred social distance.

The groups differed significantly in their belief that a child with autism can improve their language skills with the right help ($H(2) = 52.371$, $p < 0.001$). Subsequent Mann-Whitney tests indicated that HEAT+ trained ($Z=-6.24$, $p< 0.001$, $r=-.44$) and basic HEAT trained ($Z=-6.14$, $p< 0.001$, $r=-.42$) HEWs were more likely to believe that children with autism can improve their language skills compared to untrained HEWs (Table 2). The HEAT and HEAT+ groups did not differ from each other ($Z = -.46$, $p>.05$)

Figure 1 shows the mean scores and distributions of the positive beliefs (Figure 1a), negative beliefs (Figure 1b) and social distance (Figure 1c) scales in each of the three groups. There was a significant group effect on the positive beliefs scale ($F(2, 301) = 4.57$, $p=.01$, partial $\eta^2 = .03$). Planned contrasts using Bonferroni correction for multiple comparisons revealed that the

HEAT+ group had significantly lower positive beliefs scores than the untrained group (p=.01); none of the other group comparisons were significant. None of the included covariates had a significant effect on positive beliefs (all p>.05). Significant group differences were observed for the negative beliefs scores (F (2, 301) = 45.91, p<.001, partial η^2 = .23). This comparison took into account the effect of whether the surveyed HEW had a co-worker trained in mental health (F (1, 301) = 4.08, p=.04, partial η^2 = .01). Both the HEAT (p=.004) and HEAT+ group (p<.001) showed fewer negative beliefs towards children with autism than the untrained group. The HEAT+ group in turn displayed fewer negative beliefs than the HEAT group (p<.001). Significant differences were also observed between the groups' social distance scores (F (2, 301) = 103.14, p<.001, partial η^2 = .41), taking into account the effect of having a trained or untrained HEW co-worker (F (1, 301) = 4.99, p=.03, partial η^2 = .02). Both the HEAT (p<.001) and the HEAT+ group (p<.001) showed decreased social distance towards children with autism compared to the untrained group; the HEAT+ group displayed a smaller preferred social distance than the HEAT group (p=.017).

Discussion

To our knowledge this is the first study in Africa that provides evidence of the impact of both a basic and enhanced educational intervention on the beliefs and attitudes of community health workers towards children with autism. We find that both educational approaches have a significant impact in improving attitudes and negative beliefs, with more mixed findings regarding positive beliefs about children with autism.

Impact of training on positive beliefs

Compared to untrained HEWs, both the HEAT+ and the HEAT trained groups of HEWs were more likely to think that children with autism can improve their language skills with the right help. While two thirds of the HEWs not yet trained in mental health and DD thought children with autism will never or rarely improve their language with the right help, only a minority of HEAT (23%) and HEAT+ (16%) trained HEWs had such low expectations of the efficacy of a language intervention.

Against expectation, HEAT+ trained HEWs were less likely to have positive beliefs about children with autism, e.g. that they can make their parents proud, can attend school, can get married when they grow up, and can play normally with other children. This unexpected finding may perhaps be explained by the exposure of HEWs in rural Ethiopia to predominantly severe cases of autism. Identified children with autism in Ethiopia nearly always have comorbid intellectual disability (Tilahun et al., 2016). The limited positive beliefs of HEAT+ trained HEWs' may reflect their improved knowledge about autism (compared to the other two groups who received little or no autism-specific training). The practical reality is that severely affected children are unlikely to get married later, and unlikely to fit in mainstream education, in the absence of specialised autism education (Tekola et al., 2016). Our finding of no difference between the HEAT and untrained group is consistent with a number of previous mental health education studies that observed no significant change in positive attitudes or beliefs in a positive outcome for mental health patients in community health workers (Armstrong et al., 2011; Makanjuola et al., 2012) and occupational health students (Penny et al., 2001) after training.

Impact of training on negative beliefs

Compared to HEWs untrained in mental health, both HEAT and HEAT+ trained HEWs were less likely to endorse negative beliefs relating to children with autism. The HEAT+ trained group in turn endorsed fewer negative beliefs than the HEAT trained group. Importantly, HEAT or HEAT+ trained HEWs were unlikely to believe that children with autism 'need to be chained up at home', while 18% of untrained HEWs thought this would 'often' or 'nearly always' be needed. Chaining and beating children with DD is still common in Ethiopia (Tilahun et al., 2016), it is thus encouraging to see that a brief training appears to reduce the belief in this practice.

The effectiveness of the HEAT and HEAT+ programme to change negative beliefs is in keeping with previous mental health education intervention studies in health workers (Li et al., 2014; Li et al., 2015; Liu et al., 2016; Mansouri et al., 2009;) occupational health students (Penny et al., 200), police officers (Pinfold et al., 2003) and young people (Yamaguchi et al., 2011). One explanation of the greater impact of enhanced HEAT compared to basic HEAT may be the use of videos in the training. Previous mental health intervention education studies suggest that video-based education is more effective in changing attitudes than lecture-only education (Clement et al., 2013; Yamaguchi et al., 2013). An alternative explanation may be that the effect of basic HEAT training is reduced in this study as the training was provided sixteen months prior to data collection (in contrast of HEAT+, which was provided four months prior). Previous studies suggest that positive effects of mental health training may decline over time (Baxter et al., 2001; Yamaguchi et al., 2011).

Impact of training on social distance

Both the HEAT and the HEAT+ group showed reduced preferred social distance towards children with autism compared to the untrained group, suggesting decreased stigmatising attitudes. The HEAT+ group displayed a lower preferred social distance than the HEAT group. Fifty percent of the HEAT+ HEWs obtained a score of zero on the social distance scale, suggesting they have no need for social distance towards children with autism. The effect of the intervention is in keeping with previous reports that examined changes in the social distance towards people with mental health problems in community health workers (Li et al., 2014; Li et al., 2015) , police officers (Hansson and Markström, 2014) and young people (Yamaguchi et al., 2011). The result are also consistent with previous reports that video-based training is more effective in reducing social distance than lecture-only methods (Clement et al., 2013; Yamaguchi et al., 2013).

Limitations

Our study has some limitations. First, the study only included HEWs from SNNPR; views expressed by our participants may not reflect views of HEWs working in other regions. However, stigma and misconceptions about autism are widespread in sub-Saharan Africa (Bakare et al., 2009; Gona et al., 2016; Ruparelia et al., 2016), suggesting that our findings may apply more widely across Ethiopia and be relevant to settings elsewhere in Africa. Second, although we tried to limit social desirability bias by employing independent data collectors of similar socio-economic status to the participants, it is conceivable that socially desirable responding may have played a role. Against this interpretation, the HEWs who took part in our initial evaluation of HEAT (Tilahun et al., 2017) appeared open to share their opinion on what they did not like about the programme (for example, dissatisfaction that the original HEAT

materials were only available in English, rather than Amharic). A third limitation is that our groups were not perfectly matched: The HEAT group was significantly older and had longer work experience as HEW compared to the other two groups, and the untrained group had a slightly higher mark in high school compared to the HEAT group. Moreover, the time lag in between the survey and the HEAT and HEAT+ training was different: the HEAT group had completed their training sixteen months prior, while the HEAT+ group had completed their training only four months prior. Differences between the HEAT and HEAT+ group may thus also be explained by this time lag difference. Fourth, the enhanced HEAT materials included both a DVD and a mental health pocket guide. From our current study we cannot deduce whether it was the exposure to video materials or access to the pocket guide or both that generated the impact in the HEAT+ group. A final limitation is that this study did not consider whether the training had a direct impact on children with autism and their families. Our study is limited to self-reported beliefs and attitudes; future studies are warranted to examine whether these self-reported changes in beliefs and attitudes translate into tangible differences for families with children with autism.

Implications

Our finding that a brief training on mental health and DD is associated with decreased negative beliefs and an increased willingness to have contact with children with autism and their parents bodes well for the role community health workers could play in decreasing stigma in the community and in community rehabilitation for children with DD. Apart from health prevention and treatment activities, a main responsibility of Ethiopian HEWs concerns outreach services, including home visits and raising health awareness in their local community. Decreased negative

beliefs amongst HEWs may contribute to decreased stigma and negative beliefs in the community as a whole; decreased social distance from HEWs to families with a child with autism is likely to facilitate community rehabilitation, for example through the use of non-specialist workers to administer psychosocial interventions in the community (Patel et al., 2013).

The mixed effects of the HEAT+ training on positive beliefs about children with autism highlights the need for carefully designed educational interventions, taking into account the local practical and sociocultural context. The finding of a stronger effect of HEAT+ compared to HEAT training (with the caveat of the greater time lag in the HEAT group) echoes the emerging finding in mental health education research that different forms of training do not all create the same effect, and video presentations may be an especially powerful training method to reduce stigma, especially in training situations where direct social contact is not feasible (Clement et al., 2012; Yamaguchi et al., 2013).

The HEAT and HEAT+ study materials are open educational resources that are free to be adapted and used elsewhere. Given that similar challenges related to autism and mental health are reported elsewhere, the lessons learned in this study are likely to have relevance for training community health workers in other low-resource settings. A recent review highlighted the lack of evidence for interventions to reduce mental health-related stigma conducted in LMIC (Thornicroft et al., 2016). Our findings are thus likely to be relevant to addressing stigma relating to a broader range of mental health and developmental conditions too.

Conclusion

This study suggests that a two-week training course on mental health and DD has a significant impact in decreasing community health workers' negative beliefs and social distance towards children with autism and their parents. Training delivered in a widely used Ethiopian language, including video materials and a pocket guide, proved especially effective in decreasing negative attitudes and social distance, though was unsuccessful in increasing positive attitudes. Future research needs to investigate how beliefs in a positive outcome can be preserved while developing an increasing awareness about autism in challenging low-resource settings. The findings presented here are likely to be relevant for task-sharing and scale up of services for children with DD in low-resource settings worldwide.

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Table 1: Participants' socio demographic characteristics in all three study groups

Characteristic	Untrained	HEAT trained	HEAT+ trained
Mean age (years)	25.6 ±3.3	27.0±3.5*	25.4 ±3.5
Mean work experience (months)	78.1 ± 19.2	86.9±19.4*	78.7±17.7
Religious affiliation	N (%)	N (%)	N (%)
Muslim	11 (10.2)	13 (12.5)	6 (6.2)
Orthodox Christian	11 (10.2)	19 (18.3)	24 (24.7)
Catholic	3 (2.8)	2 (1.9)	1 (1.0)
Protestant	83 (76.9)	69 (66.3)	65 (67.0)
Other	0 (0)	1 (1.0)	1 (1.0)
HEAT-trained colleague employed in same community	N (%)	N (%)	N (%)
No	102 (94.4)	96 (92.3)	92 (94.8)
Yes	6 (5.6)	8 (7.7)	5 (5.2)
Mean of mark in high school	2.25 ±0.29	2.13±0.26[$]	2.21±0.26
Grade they completed at school	N (%)	N (%)	N (%)
Grade 10	73 (67.6)	63 (60.0)	71 (73.2)
Grade 12	35 (32.4)	42 (40.0)	26 (26.8)

* significantly different from other two groups, $p < 0.01$

[$] significantly different from untrained group only, $p < 0.01$

Table 2: Positive beliefs towards children with autism in untrained, HEAT trained and HEAT+ trained HEWs

Items	Untrained	HEAT trained	HEAT+ trained
	N (%)	N (%)	N (%)
Single item: positive belief in effect language intervention			
Can improve their language skills with the right help			
Never	24 (22.2)	6 (5.7)	4 (4.1)
Rarely	45 (41.7)	18 (17.1)	12 (12.4)
Often	19 (17.6)	26 (24.8)	39 (40.2)
Nearly always	20 (18.5)	54 (51.4)	42 (43.3)
Positive beliefs scale			
Can make their parents proud			
Never	60 (55.5)	77 (74.1)	84 (86.6)
Rarely	14 (13.0)	20 (19.2)	5 (5.2)
Often	20 (18.5)	5 (4.8)	5 (5.2)
Nearly always	14 (13.0)	2 (1.9)	3 (3.0)
Can attend school			
Never	54 (50.0)	39 (37.5)	51 (52.6)
Rarely	38 (35.2)	46 (44.2)	41 (42.3)
Often	8 (7.4)	14 (13.5)	3 (3.1)
Nearly always	8 (7.4)	5 (4.8)	2 (2.0)

Can get married when they grow up			
Never	59 (54.6)	37 (35.6)	46 (47.4)
Rarely	38 (35.2)	49 (47.1)	35 (36.1)
Often	7 (6.5)	14 (13.5)	11 (11.3)
Nearly always	4 (3.7)	4 (3.8)	5 (5.2)
Can play normally with other children			
Never	65 (60.2)	65 (62.5)	68 (70.1)
Rarely	28 (25.9)	26 (25.0)	25 (25.7)
Often	9 (8.3)	6 (5.8)	2 (2.1)
Nearly always	6 (5.6)	7 (6.7)	2 (2.1)

Table 3: Negative beliefs towards children with autism in untrained, HEAT trained and HEAT+ trained HEWs

Items	Untrained	HEAT trained	HEAT+ trained
	N (%)	N (%)	N (%)
Are a public nuisance due to poor hygiene or odd behaviour			
Never	12 (11.1)	7 (6.7)	37 (38.1)
Rarely	45 (41.7)	39 (37.5)	29 (29.9)
Often	26 (24.1)	32 (30.8)	22 (22.7)
Nearly always	25 (23.1)	26 (25.0)	9 (9.3)
Can bring bad luck on the community			
Never	24 (22.2)	47 (45.2)	65 (67.0)
Rarely	39 (36.1)	36 (34.6)	21 (21.6)
Often	28 (25.9)	4 (3.9)	5 (5.2)
Nearly always	17 (15.8)	17 (16.3)	6 (6.2)
Can be seen talking to themselves			
Never	10 (9.3)	7 (6.7)	34 (35.1)
Rarely	19 (17.6)	45 (43.3)	37 (38.1)
Often	43 (39.8)	29 (27.9)	16 (16.5)
Nearly always	36 (33.3)	23 (22.1)	10 (10.3)
Are dangerous to the public because of violent behaviour			
Never	20 (18.5)	20 (19.2)	46 (47.4)
Rarely	32 (29.6)	40 (38.5)	36 (37.1)

Often	38 (35.2)	23 (22.1)	7 (7.2)
Nearly always	18 (16.7)	21 (20.2)	8 (8.3)
Need to be chained up in the home			
Never	77 (71.3)	102 (98.1)	96 (99.0)
Rarely	11 (10.2)	2 (1.9)	1 (1.0)
Often	9 (8.3)	0 (0)	0 (0)
Nearly always	11 (10.2)	0 (0)	0 (0)

Table 4: Social distance towards children with autism in untrained, HEAT trained and HEAT+ trained HEWs

Items	Untrained N (%)	HEAT trained N (%)	HEAT+ trained N (%)
Feel afraid to have a conversation with a child with autism			
Definitely not	42 (38.9)	75 (72.1)	87 (89.7)
Probably not	8 (7.4)	7 (6.7)	3 (3.1)
Probably	26 (24.1)	9 (8.7)	4 (4.1)
Definitely	32 (29.6)	13 (12.5)	3 (3.1)
Upset about working with a colleague who is a parent of a child with autism			
Definitely not	55 (50.9)	85 (81.7)	84 (86.6)
Probably not	14 (13.0)	5 (4.8)	7 (7.2)
Probably	18 (16.7)	11 (10.6)	3 (3.1)
Definitely	21 (19.4)	3 (2.9)	3 (3.1)
Able to maintain a friendship with a parent of a child with autism*			
Definitely not	50 (46.3)	19 (18.2)	10 (10.3)
Probably not	13 (12.0)	6 (5.8)	3 (3.1)
Probably	7 (6.5)	11 (10.6)	1 (1.0)
Definitely	38 (35.2)	68 (65.4)	83 (85.6)
Feel upset or disturbed about being alone in a room with a child with autism			
Definitely not	39 (36.1)	61 (58.6)	68 (70.1)
Probably not	10 (9.3)	10 (9.6)	14 (14.4)
Probably	25 (23.1)	19 (18.3)	9 (9.3)

Definitely	34 (31.5)	14 (13.5)	6 (6.2)
Feel ashamed if people knew a child in family has been diagnosed with autism			
Definitely not	55 (50.9)	88 (84.6)	87 (89.7)
Probably not	12 (11.1)	7 (6.7)	4 (4.1)
Probably	15 (13.9)	6 (5.8)	3 (3.1)
Definitely	26 (24.1)	3 (2.9)	3 (3.1)
Feel ashamed to be seen out on the street taking care of a child with autism			
Definitely not	62 (57.4)	96 (92.3)	94 (96.9)
Probably not	10 (9.3)	8 (7.7)	2 (2.1)
Probably	8 (7.4)	0 (0)	1 (1.0)
Definitely	28 (25.9)	0 (0)	0 (0)

Note: * denotes a reverse scored item in the social distance sum score

Figure 1 Positive and negative beliefs and social distance towards children with autism in untrained, HEAT trained, and HEAT+ trained HEWs

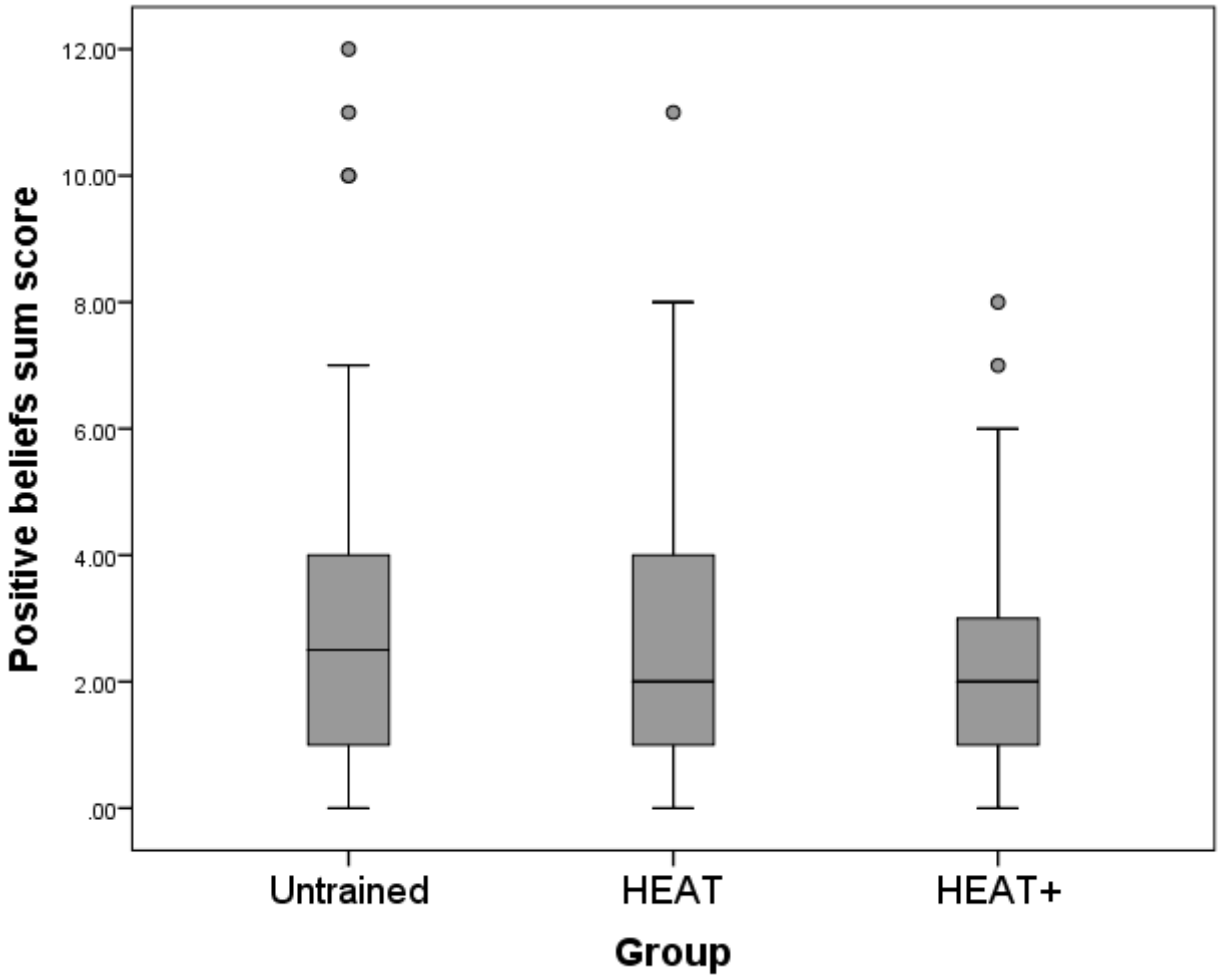

Figure 1a

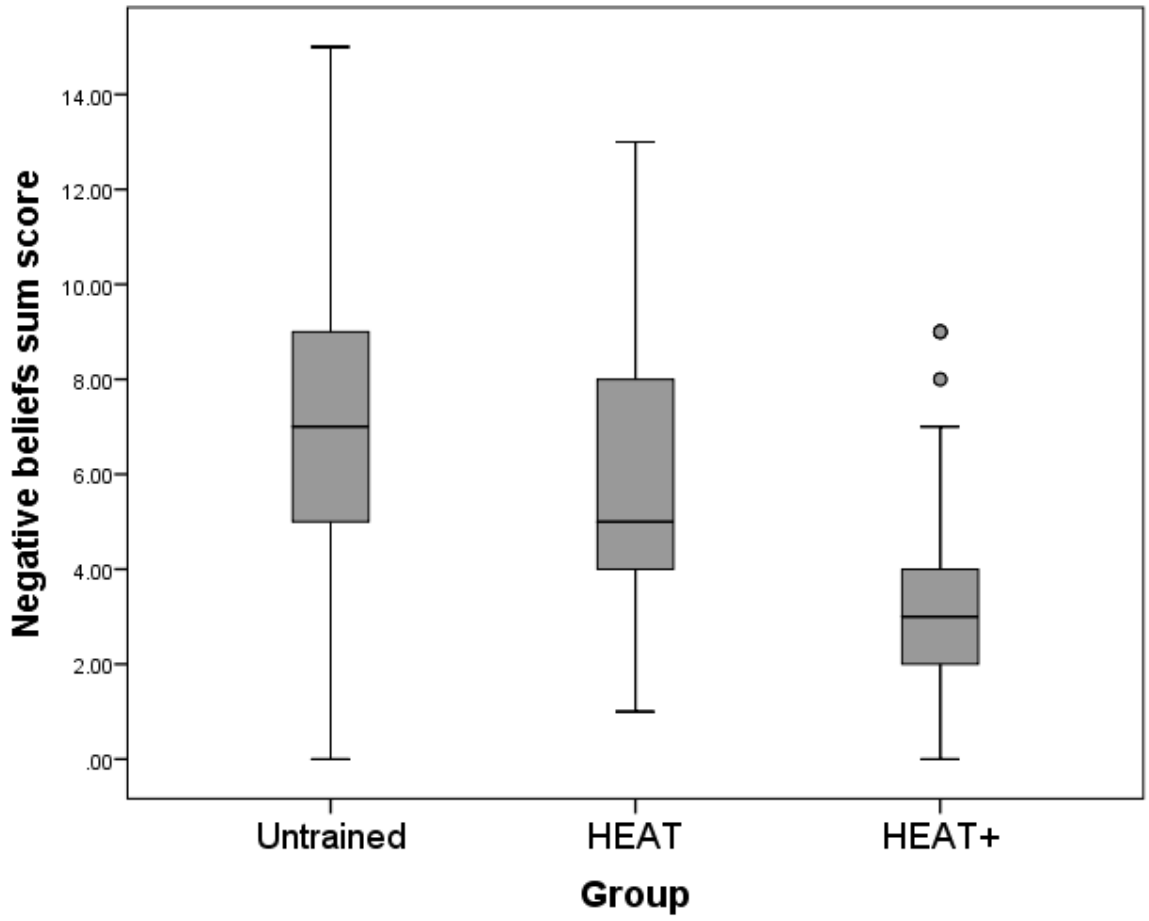
Negative beliefs sum score
14.00
12.00
10.00
8.00
6.00
4.00
2.00
.00
Untrained
HEAT
HEAT+
Group

Figure 1b

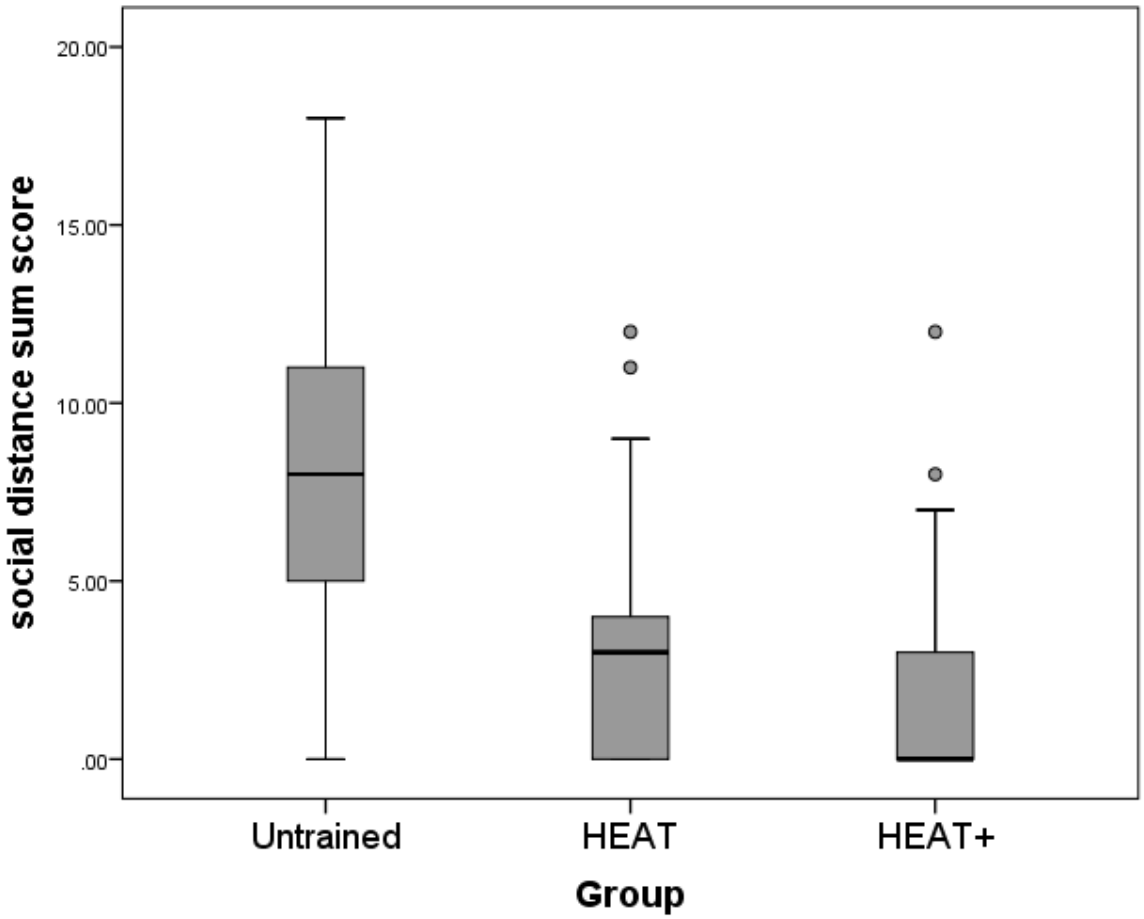

Figure 1c

Note: a higher score on the positive beliefs (Figure 1a) and negative beliefs (Figure 1b) scales indicates stronger beliefs; a lower social distance score (Figure 1c) indicates less desire to keep a distance from the child with autism suggesting decreased stigmatising attitudes

Annex 2: Health Extension Workers and parents Information sheet, consent form and debriefing

Annex 2.1. **Health Extension Workers Information sheet, consent form and debriefing**

Title of the project: "***Impact of training health extension workers in relation to child mental health care, Ethiopia***"

Principal Investigator: Dejene Tilahun

Supervisor: **Dr. Abebaw Fikadu**

Coordinating office: Addis Ababa University, Department of Psychatry

Information sheet

People in your community with mental health problems: An interview based study

We would like to invite you to participate in our research project. Before you decide whether you would like to take part, it is important for you to understand why the study is done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear, feel free to ask us for more information.

What is the purpose of the research project?

This study is looking into the experiences of health extension workers with people with mental health problems. We would like to learn more about health extension workers' views on these illnesses, and what kind of care you think people with mental health problems get in your community. We are also interested in your experience with children in your community who develop slower than normal and who may need additional care.

We have written teaching material that addresses mental health problems and developmental problems in childhood, and some of you may have studied this material as part of your health education. With the results from this survey we hope to improve our existing teaching material, so that future health extension workers can benefit from high quality teaching material that is tailored to the needs in the local community.

Who are we asking to take part in this study?

We were invited a large group of health extension workers in Ethiopia to take part in this project. We were also interviewing the parents of children who develop slowly.

What will happen if you agree to take part?

You will be invited to a health science college near your area. The data collector will ask you questions from a questionnaire. After completion the data collector will put the questionnaire in a sealed envelope.

What about privacy and confidentiality?

The questionnaires were not included your name, just a code number. Only the project coordinators and the data collector will know your name, and only they will know that the information you have provided belongs to you. Your personal details will be stored separately from the questionnaire, in a locked cabinet. We will also store the questionnaires in a locked cabinet, and if we enter the data onto a computer then we will make sure that this data is securely stored. The information you provide will be kept strictly confidential, only members of the research group will have access to the data. This questionnaire is not an examination, and the information you give will not be shared with your tutor or with your line manager at work. We can only improve the teaching material if you tell us honestly what you think. We will not tell anyone outside the research team what you have responded, so please give us your truthful answers.

What will happen to the study results?

Based on the information that you and many other health extension workers provide, we will revise the current teaching material on mental health problems and childhood problems. We will also look at the results overall, and present our findings to other researchers. All results will be presented without giving any personal details about you, so other researchers will not be able to identify you.

Once the study is completed, we will let you know what we found by giving you a leaflet summarising the overall results, but without mentioning any health extension worker by name.

What happens if I decide not to take part in this study (**the right of the participant*****)?***

Your participation in this study is entirely voluntary. Even after you started the interview, you are free not to respond or to stop without providing us with an explanation.

You can withdraw from the study up to the end of December 2013.

If you wish to withdraw from the study, please contact the researchers as described below. We can destroy the data you have provided us with if you instruct us to do so. Choosing not to take part in this study will not disadvantage you in any way.

Who has reviewed the study?

The ethics protocol of this study has been reviewed and approved by the ethics committee of the College of Health Sciences of Addis Ababa University and by the Open University's Human Research Ethics Committee.

I have some more questions about the research. Who can I speak to?

Please contact **[Dejene Tilahun]** on **[0911811301]** or email **[dejentn@yahoo.com]**.

If you would like to talk to someone else about this project, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University **[telephone number]**.

Thank you for reading this.

Consent form

People in your community with mental health problems:

An interview based study

Agreeing to take part

- I confirm that I have read and understand the information sheet for this study
- I understand that I can withdraw from this study at any time without having to give any reasons for doing so (up until the end of December 2012[1]).
- I consent to the processing of my personal information for the purposes explained to me. I understand that my identity will remain confidential and all the information I provide will be handled in accordance with the terms of the Ethiopian and United Kingdom data protection rules.
- I agree that the information that I provide can be used for educational or research purposes, including publication. In these publications, my confidentiality and anonymity will be maintained and it will not be possible to identify me.
- I understand that if I have any concerns or difficulties I can contact the study researchers at the telephone number [0911811301]

Signed:……

Date:……

Debrief

People in your community with mental health problems: An interview based study

Thank you very much for taking part in our study; the information you have provided will greatly help us in improving our existing teaching material for health extension workers and make sure that it is tailored to the needs in the local community.

If you have any questions about this study, our research team would be happy to speak to you. Please contact **[researcher name]** on **[telephone number]** or email **[email address]**.

If you would like to talk to someone else about this project, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University **[telephone number]**.

If you would like to withdraw from the study, please contact us on **[telephone number]** or email **[email address]** and we will make sure to remove the information you have provided from our database. Your data can be removed up until December 2012.

Once the project is completed, we will let you know what we found by giving you a leaflet summarizing the overall results. All results will be presented without mentioning the names of the health extension workers who took part, so no-one will be able to identify you.

Many thanks again for your participation.

Annex 2.1.2. **Parents Information sheet, consent form and Debrief:**

Information sheet

Being the parent of a child who develops slowly: An interview study

We would like to invite you to participate in our research project. Before you decide whether you would like to take part, it is important for you to understand why the study is done and what your participation will involve. Please listen to me carefully while I read out the following information. Please discuss it with others if you wish. If there is anything that is not clear, feel free to ask us for more information.

What is the purpose of the research project?

We would like to learn about your child's problem with developing slowly. The information you give us will help to improve the training of health extension workers and to work out how we can develop services to support you.

We have written teaching material, studied by health extension workers, that addresses childhood problems. With the results from this study we hope to improve our existing teaching material, so that future cohorts of health extension workers can benefit from high quality teaching material that is tailored to the needs of the local community.

Who are we asking to take part in this study?

We will be interviewing a group of parents like you, who all have a child who develops slowly. We will also invite a group of health extension workers will also invited to take part in this project.

What will happen if you agree to take part?

We will ask you some brief questions about your background followed by some questions about your experience of being a parent to a child who develops slowly.

Will other people be able to identify me from the information I give to you?

On the written material we will use a code number instead of your name so that only the research team will know that this information comes from you. The code and your name will be kept in a separate, locked cupboard.

What will happen to the study results?

Based on the information that you and other families give us, we will revise the current teaching material on childhood problems. We will also present our findings to other researchers. All results will be presented without giving any personal details about you, so other researchers will not be able to identify you.

What happens if I decide not to take part in this study (*the right of the participant*)?

Your participation in this study is entirely voluntary. Even after you have received the questionnaire and have started to fill it out, you are free to decide not to give the questionnaire back to us without providing us with an explanation.

You can withdraw from the study up until the final data are published.

If you wish to withdraw from the study, please contact the researchers as described below. We can destroy the data you have provided us with if you instruct us to do so. Choosing not to take part in this study will not disadvantage you in any way.

Who has reviewed the study?

The ethics protocol of this study has been reviewed and approved by the ethics committee of the College of Health Sciences of Addis Ababa University and by the Open University's Human Research Ethics Committee.

I have some more questions about the research. Who can I speak to?

Please contact **[Dejene Tilahun]** on **[0911811301]** or email **[dejentn@yahoo.com]**.

If you would like to talk to someone else about this project, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University **[telephone number]**.

Thank you for reading this.

Consent form

Being the parent of a child who develops slowly: An interview study

Agreeing to take part

- I confirm that I have read and understand the information sheet for this study
- I understand that I can withdraw from this study at any time without having to give any reasons for doing so (up until December 2012).
- I consent to the processing of my personal information for the purposes explained to me. I consent that the interview will be recorded for research purposes.
- I understand that my identity and everything I say in the interview will remain confidential. I understand that all the information I provide will be handled in accordance with the terms of the Ethiopian and United Kingdom data protection rules.
- I agree that the information that I provide can be used for educational or research purposes, including publication. In these publications, my confidentiality and anonymity will be maintained and it will not be possible to identify me.
- I understand that if I have any concerns or difficulties I can contact the study researchers at the telephone number [0911811301]

Signed:……

Date:……

Debrief

Being the parent of a child who develops slowly: An interview study

Thank you very much for taking part in our study; the information you have provided will greatly help us in improving our existing teaching material for health extension workers and make sure that it is tailored to the needs in the local community.

If you have any questions about this study, our research team would be happy to speak to you. Please contact **[Dejene Tilahun]** on **[0911811301]** or email **[dejentn@yahoo.com]**.

If you would like to talk to someone else about this project, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University **[telephone number]**.

If you would like to withdraw from the study, please contact us on **[Dejene Tilahun]** on **[0911811301]** or email **[dejentn@yahoo.com]**. And we will make sure to remove the information you have provided from our database. Your data can be removed up until December 2012.

If you would like to speak to someone with expertise in your child's problems, you can come to the child mental health services at Yekatit 12 hospital.

Many thanks again for your participation.

Annex 3: Data Collection Tool for Health Extension workers and Parents

Annex 3.1. Child mental health problems in the community questionnaire (Health extension worker questionnaire)

Mental health problems in your community Questionnaire

TITLE PAGE

This questionnaire needs to be completed by the **Health Extension Worker** and **data collectors**

Instructions for data collectors: the underlined text below needs to be read out to the Health Extension Worker

This page will be kept and stored separately from the questionnaire. No-one outside the research team will know that the information you will provide in the questionnaire belongs to you. All your answers will remain strictly confidential. The information you give will not be shared with your tutors or supervisors.

Your name:_____

I work in the following *kebele*: _____
This *kebele* is part of the following *woreda*: _____

If you have completed the Health Extension Worker level IV training, or are currently studying this training:
At which Health Science College did/do you study? _____

Today's date: Day: ____ Month: _____ Year: _____ E.C.

Instructions for data collector: Please check that that the 4-digit code on the top of this title page is also written down on the top of the next page (at the start of the questionnaire).
After you and the Health Extension Worker have filled out this title page, please remove this page and store it away in an envelope. Complete the remainder of the questionnaire with the Health Extension Worker in a quiet place with no-one else around.

Mental health problems in your community Questionnaire

Section 1. PERSONAL DETAILS					
If you don't mind, I'd like to start by asking you a few questions about yourself.					
101	**How old are you?**	**Years**			**AGEYRS**
101.1	**Today's date:**	**Day: ___Month: ____Year: ____E.C**			**DOI**
102	What is your religious affiliation?	Muslim		**1**	**RELIG**
		Orthodox christan		**2**	
		Catholic		**3**	
		Protestant		**4**	
		No religion		**5**	
		Other (specify) _____		**66**	
		Refused / No Answer		**99**	
103	How long have you worked as a Health Extension Worker?	**___Years ____ Months**			**SERVLENG**
103.1	ONLY ANSWER IF YOU HAVE PREVIOUSLY WORKED AS A HEALTH EXTENSION WORKER IN ANOTHER KEBELE: How long have you worked as a Health Extension Worker in the *kebele* you are currently working?	_____ Years _____ Months:			OTHRSERV
104	What is the highest grade you completed at school?	_____ grade			**EDUCOMPT**
104.1	Which level of Health Extension Worker education have you completed? (*please tick one*):	10+ 1 certificate	EDUCOMPT	**1**	**EDULEVEL**
		12+ 1 certificate		**2**	
		Health Extension Worker upgrading (Level IV) diploma		**3**	
		I am studying for the Health Extension Worker upgrading Level IV diploma, but have not yet		**4**	

		completed			
		Other (specify)		**66**	
104.2	What was your mark in high school (10^{th} grade)?	_____			**EDUGRAD**
104.3	How many model households have graduated in your *kebele*?	_____			**MODELFAM**
105.4	Do you work with another Health Extension Worker in your *kebele*?	No		**0**	OTHRHEW
		Yes*		**1**	
105.5	*If Yes, has your colleague yet completed the HEW level IV training?	NO		**0**	COMPTRAN
		Yes		**1**	

Section 2: Childhood problems.

Below and on the next pages you will find two case studies. Please read each case study carefully and then answer the questions beneath.

Case study: a boy called Girma

On one of your home visits a mother expresses her concerns about her son, called Girma. Girma is 8 years old and doesn't talk. Girma's mum says he doesn't make any eye contact when she speaks to him, and when she calls out his name he doesn't respond. You do a hearing check and find that Girma doesn't have a hearing problem. You have a long chat with Girma's mother and father. They clearly love their son a lot. Even though they encourage him to play with other children, they find that Girma doesn't play with other children of his age. He plays with the same thing again and again. He also likes precisely lining up household items. Girma gets really upset when someone moves something and thereby ruins the order. When he gets upset he screams loudly and rocks his body back and forth. His parents find it very difficult to console him when he is upset.

A. Below is a list of characteristics For each behaviour please respond how common you think these characteristics occur in children with autism						
	Do you believe that children with autism	**Nearly always (3)**	**Often (2)**	**Rarely(1)**	**Never (0)**	
1001	Can improve their language skills with the right help	**3**	**2**	**1**	**0**	**LANGUAGE**
1002	Are a public nuisance due to poor hygiene or odd behaviour	**3**	**2**	**1**	**0**	**HYGIENE**
1003	Can bring bad luck on the community	**3**	**2**	**1**	**0**	**BADLUCK**
1004	Can be seen talking to themselves or	**3**	**2**	**1**	**0**	**SHOUT**

	shouting outside					
1005	Can make their parents proud	**3**	**2**	**1**	**0**	**PROUD**
1006	Can attend school	**3**	**2**	**1**	**0**	**ATENDSCHL**
1007	Are dangerous to the public because of violent behaviour	**3**	**2**	**1**	**0**	**DANGER**
1008	Can get married when they grow up	**3**	**2**	**1**	**0**	**MARRIED**
1009	Can play normally with other children	**3**	**2**	**1**	**0**	**NORMAL**
1010	Need to be chained up in the home	**3**	**2**	**1**	**0**	**CHAINED**

B. please respond how you would feel in each of the following situations						
		Definitely(3)	**I think so (2)**	**Probably not (1)**	**Definitely not (0)**	
2001	Would you feel afraid to have a conversation with a child with autism	**3**	**2**	**1**	**0**	**AFRAIDCONV**
2002	Would you be upset or disturbed about working with a colleague who is a parent of a child with autism?	**3**	**2**	**1**	**0**	**UPSETJOB**
2003	Would you be able to maintain a friendship with a parent of a child with autism?	**3**	**2**	**1**	**0**	**MAINTANFRD**
2004	Would you feel upset or disturbed about being alone in a room with a child with autism?	**3**	**2**	**1**	**0**	**ALONEROM**
2005	Would you feel ashamed if people knew a child in your family has been diagnosed with autism?	**3**	**2**	**1**	**0**	**ASHMEKEW**
2006	Would you feel ashamed to be seen out on the street taking care of a child with autism?	**3**	**2**	**1**	**0**	**ASHMSTRET**

Section 3: Your training in mental health problems and childhood problems					
<u>You only need to complete this section if HEWs completed the level IV Health Extension Programme training. If not (yet) completed this training, please proceed to section VIII</u>					
	I would like to ask you about...				
3001	Have you completed Non-Communicable Diseases Part 2 module of the level IV upgrading Health Extension Programme?	No		**1**	**COMPNCD**
		Yes*		**2**	

3001.1	*If Yes, how long ago (indicate number of years/ months ago)?	___Years ___Months			**COMPLGTH**
3002	Did your mental health training include any practical component?	No		**1**	**TRAINPRAC**
		Yes*		**2**	
3002.1	*If Yes, please specify:	_____			**TRANTYPE**
3003	When you completed the mental health part of the training, did you have your own copy of the study text on mental health and childhood behavioural and developmental problems?	Yes		**1**	**TRANCHBD**
		No, but I could access the study material in the library		**2**	
		No, I did not have access to the material*		**3**	
3003.1	* If you did not have access to the material, please skip question **704** to 707 and continue with question **708** on the next page.				
3004	What was your overall opinion of the quality of the study text on mental health and childhood behavioural and developmental problems?	Extremely poor		**1**	**TRANQUAL**
		Below average		**2**	
		Average		**3**	
		Above average		**4**	
		Excellent		**5**	
3005	Overall, did you find the Mental Health and childhood problems study text interesting to study?	Not at all interesting		**1**	**MHACHINT**
		Of little interest		**2**	
		Moderately interesting		**3**	
		Interesting		**4**	
		Very interesting		**5**	
3006	Do you have any suggestions on how the Mental Health and childhood problems study text can be improved?	_____			**MHACHIMP**
3007	Do you feel that there was any information missing from the Mental Health and childhood problems study text? If so, what would you like to see included?	_____			**INFOMISS**
3008	Do you feel that the topic of mental health problems is important for a Health Extension Worker?	Not at all important		**1**	**TOPMHIMP**
		Of little importance		**2**	
		Moderately important		**3**	
		Important		**4**	
		Very important		**5**	
3009	Do you feel that the topic of childhood behavioural and developmental problems is important for a Health Extension Worker?	Not at all important		**1**	**TOPCHIMP**
		Of little importance		**2**	
		Moderately important		**3**	
		Important		**4**	
		Very important		**5**	

3010	Do you use any of the training provided in the Mental Health and childhood problems study material in your work?	No, never		**1**	**USETRANMAT**
		Yes*, but only rarely (once or twice a year)		**2**	
		Yes*, sometimes (about once a month)		**3**	
		Yes*, often (about once a week)		**4**	
		Yes*, very often (more than once a week)		**5**	
3010.1	*If Yes, how did the training help you in your daily work? (Please give a description):	_____			**HOWTRHLP**
3011	Have you organised a mental health awareness meeting in your community?	No, never*		**1**	**ORGTRAIN**
		Yes, but only once**		**2**	
		Yes, two or more meetings**		**3**	
3011.1	* If no: can you explain why not?	_____			**WHYNO**
3011.2	**If yes: please give details about what you discussed in the community meeting:	_____			**WHATDISC**
3012	Apart from the Mental Health and childhood problems study material in the Health Extension Programme, what other sources of information do you have, or have you used, regarding mental health problems and childhood behavioural and developmental problems? (*please tick all that apply*)	No other sources		**1**	**OTHRSOUR**
		Information from other Health Extension Workers		**2**	
		Information from another medical professional(s)		**3**	
		Information from a traditional healer		**4**	
		Information from a religious leader (church or mosque)		**5**	
		I have read books (other than the level IV study material) on the topic		**6**	
		I have seen programmes on the topic on TV		**7**	
		I have listened to radio programmes on the topic		**8**	
		Other source (please specify): _____ _____		**66**	
If you have completed the level IV upgrading Health Extension Programme training then this is the final question for you. Thank you very much for completing this questionnaire.					

Annex 3.2. In Depth interview topic guide for HEAT trained health extension workers

In Depth interview guide for HEWs for evaluation of the impact of the current mental health module within the HEAT curriculum

You received some training in mental health problems and/or child hood disorders as part of the level IV upgrade.

1. Can you tell me about how you found the training of child developmental disorders
2. Did you face any barriers when you were learning the materials on childhood developmental disorders? (Probe further, e.g.: tutor did not focus on the childhood problems chapter; chapter was difficult to understand b/c of language etc.)?
3. Tell me about how that training/training material has affected your practice in child developmental disorders (autism)?
4. [If the training hasn't affected the HEW's practice] Can you tell me about that - why do you think it is? Do you have any suggestions for how such training could make more of a difference in child developmental disorders / autism?
5. [If the training has affected the HEW's practice] Can you tell me about some of the activities you have been involved in? Awareness-raising? Detecting new cases? Advising families? Referring families? Mobilizing the community to provide support to families...? Tell me about particular cases where you have been involved in child developmental disorders / autism.
    - What exactly did you do? How did you feel about doing these activities? Would you do them again? How would you advise other HEWs to get started with these activities in child developmental disorders / autism?
6. From the child developmental disorders / autism training, which parts do you think helped you to be able to use the training in practice? How was that?
7. What could be improved in the child developmental disorders / autism training so that you would be able to use it more in your day-to-day work?
8. Are there other factors that affect doing this kind of work (meaning providing care for children who have developmental problems / autism)? E.g. PROBE time constraints, fearful to have contact with such families, got more important work to do, not worth doing because can't cure in child developmental disorders / autism?

Annex 3.3. Structured questionnaire for parents of children with developmental disorder (intellectual disability and autism)

This page to be removed after interview and kept in a separate, secure location.

Project ID number:

Hospital registration number _____

Name of child:

Home address_____district_____kebele_____

Telephone number_____

Study site Yikatit_____St Paul's_____

Rural area (specify woreda _____)

Interviewer's name_____signatur_____

Field supervisors_____signature_____

A. Introduction to the project:

To data collectors: Say your name and where you are from and briefly introduce the project by saying:

We are here to learn about your child's developmental problems and the effect these have had on your family. The information you give us will help to improve the training of health workers and work out how we can develop services to support you.

Section 1. From medical records/parents					
101	**Project ID Number:**	**[ ] [ ] [ ]**			**PIDN**
102	Health facility:	Yekatit 12		**1**	**NAMEHF**
		St Paul's		**2**	
103	Chief complaint	[ ]----------		**1**	**CHIEFCOMP**
		[ ] ----------		**2**	
		[ ] ----------		**3**	
		[ ] ----------		**4**	
104	Date of diagnosis	**____Date ___ Months ____ Years**			**DATEDX**
105	Date treatment started	**____Date ___ Months ____ Years**			**DATERX**
106	Onset of child's problem (age of onset)	_____ Years _____ Months:			**AGEONSET**
107	CARS score:	_____			**CARESCOR**

Section 2: Background					
If you don't mind, I'd like to start by asking you a few questions about yourself.					
201	What age are you now?	**Years**			**AGEYRS**
201.1	Date of Birth (if known) d/m/y	_____ year			**DOB**
201.2	Today's date	___ ___/___ ___/___ ___ ___ ___ E. C.			**TODYDAT**
202	How many children do you have?	[ ] [ ]			**NUMBCHLD**
203	How old is the child with developmental problems?	[ ] years			**CHDEVDS**
203.1	Date of birth (if known)	___ ___/___ ___/___ ___ ___ ___ E. C			**DATEBRTH**
204	Is this child a boy or a girl?	Boy		**1**	**SEX**
		Girl		**2**	
205	Do any of your other children have developmental problems?	No		**1**	**CHDEVDS**
		Yes		**2**	
205.1	If yes, please give details about their problems:				**PROBLEM**

206	What is the highest level of formal education you have completed?	No formal education		**1**	**EDUCLEVL**
		Completed grade (1-12)		**2**	
		Diploma		**3**	
		Degree		**4**	
		Master		**5**	
207	What is your marital status?	Married		**1**	**MARITAL**
		Never married		**2**	
		Separated		**3**	
		Divorced		**4**	
		Widowed		**5**	
		N/A		**6**	
208	Ethnicity	Amhara		**1**	
		Oromo		**2**	**ETHNIC**
		Tigrie		**3**	
		Gurage		**4**	
		Welayta		**5**	
		Sidama		**6**	
		Hadiya		**7**	
		Gamo		**8**	
		Other (specify)		**66**	
209	What is your religion?	No religion		**1**	**RELGN**
		Orthodox Christian		**2**	
		Catholic		**3**	
		Protestant		**4**	
		Muslim		**5**	
		Other specify		**6**	
210	**What is your occupation?**	Farmer		**1**	**OCCUP**
		Housewife		**2**	
		Government employee		**3**	
		Trader		**4**	
		Student		**5**	
		Unemployed		**6**	
		private employee		**7**	
		Other (specify)		**66**	
211	**What is your residence?**	Urban		**1**	**RESIDENC**
		Rural		**2**	

Section 3: Question about your family and your child						
Can you please tell me whether any of the following things have happened since your child (name) developed problems?						
		Not at all (0)	Sometimes (1)	Often (2)	A lot (3)	
301	Worried about being treated differently	**0**	**1**	**2**	**3**	**WORYRX**
302	Worried other people would find out about it	**0**	**1**	**2**	**3**	**WORYOTHR**
303	Felt the need to hide this problem from people (i.e. that your child has problems)	**0**	**1**	**2**	**3**	**HIDEPRBM**
304	Helping other people to understand what it is like to have a child with slow development	**0**	**1**	**2**	**3**	**HELPOTHR**
305	Have you made an effort to keep this problem a secret?	**0**	**1**	**2**	**3**	**SECRETPRB**
306	Worried about being avoided	**0**	**1**	**2**	**3**	**WORYAVOD**
307	Explaining to others that (your child) isn't like their picture of "crazy" people	**0**	**1**	**2**	**3**	**EXPLAIN**
308	Worried that people would blame you for his or her problems	**0**	**1**	**2**	**3**	**BLAME**
309	Worried that a person looking to marry would be reluctant to marry into your family	**0**	**1**	**2**	**3**	**MARRY**
310	Worried about taking him or her out	**0**	**1**	**2**	**3**	**TAKINGOUT**
311	Felt ashamed or embarrassed about it	**0**	**1**	**2**	**3**	**EMBARSED**
312	Sought out people who also have a child with similar problems with developing slowly	**0**	**1**	**2**	**3**	**SIMLARPRB**
313	Felt grief or depression because of it	**0**	**1**	**2**	**3**	**GRIEF**
314	Felt that somehow it might be your fault	**0**	**1**	**2**	**3**	**FAULT**

315	What do you think is the most likely cause of your child's problems with slow development?	1 2..			CAUSECHD
	Do you think the cause could be any of the following:				
315.1	Spirit possession?	No		1	SPIRIT
		Yes		2	
315.2	Punishment from God?	No		1	PUNSHGOD
		Yes		2	
315.3	Sinful act?	No		1	SINFUL
		Yes		2	
315.4	Pathogen / infectious cause?	No		1	PATHOGN

		Yes		2	
315.5	Evil eye?	No		1	EVILEYE
		Yes		2	
315.6	Family history?	No		1	FAMILYHX
		Yes		2	
315.7	Birth complications	No		1	BIRTHCOMP
		Yes		2	
315.8	Head injury(because of hitting the head) ?	No		1	HEADINJU
		Yes		2	
315.9	Eplipsy?	No		1	EPLIPSY
		Yes		2	
315.10	Drinking alcohol in pregnancy?	No		1	ALCOLPRG
		Yes		2	
315.11	Chewing khat in pregnancy?	No		1	KHAT
		Yes		2	
315.12	Curse / bewitchment?	No		1	CURSE
		Yes		2	
315.13	Don't know	No		1	DONTKNO
		Yes		2	W
315.14	Other specify				
316	Do you think your child's condition can be transmitted to other people?	No		1	TRANSMIT
		Yes		2	
317	Do you think other people think that your child's condition can be transmitted to other people?	No		1	OTRTHTRA
		Yes		2	
318	If yes to 17 or 18, describe how this might happen	1. 2.			MECATRA
321	Where did you first look for help for your child's difficulty of developing slowly?	1. 2.			FIRSTHELP
	Have you looked for help from any of the following:				
319.1	Holy water?	No		1	HOLYWATR
		Yes		2	
319.2	Church / priest?	No		1	CHURCH
		Yes		2	
319.3	Debtera	No		1	DEBTERA
		Yes		2	
319.4	Kalicha?	No		1	KALICH
		Yes		2	
319.5	Mosque	No		1	MOSQ
		Yes		2	
319.6	Tanquaye?	No		1	TANQY
		Yes		2	

319.7	Wogesha?	No		1	WOGSHA
		Yes		2	
319.8	Herbalist?	No		1	HERBALST
		Yes		2	
321.9	Health extension workers	No		1	HEW
		Yes		2	
321.10	Public health center,	No		1	PHC
		Yes		2	
321.11	Hospital	No		1	HOSP
		Yes		2	
321.12	Private clinic?	No		1	PRIVCLNC
		Yes		2	
321.13	Private pharmacy?	No		1	PRIVPHAR
		Yes		2	
321.13	Other (specify)				
320	What type of treatment have you tried for your child's difficulty of developing slowly?	1. 2.			RXTYPE
	Have you tried any of the following?				
320.1	Tablets from health facility?	No		1	TABLET
		Yes		2	
320.2	Injection from health facility?	No		1	INJEC
		Yes		2	
320.4	Chaining?	No		1	CHAIN
		Yes		2	
320.5	Beating?	No		1	BEAT
		Yes		2	
320.6	Fumigating?	No		1	FUMIGAT
		Yes		2	
320.7	Prayer?	No		1	PRAYER
		Yes		2	
320.8	Slaughtering a sheep?	No		1	SLAUTER
		Yes		2	
320.9	Kitab?	No		1	KTAB
		Yes		2	
320.10	Other specify:				
321	What do you do to help cope (personally) with your child's difficulty of developing slowly?	1. 2.			COPECHDS
	Do you cope with any of the following strategies:				
321.1	Talking to family?	No		1	FAMTALK
		Yes		2	

321.2	Talking to friends?	No		1	FRNDTALK
		Yes		2	
321.3	Talking to health professional?	No		1	PROFTALK
		Yes		2	
321.4	Prayer?	No		1	PRAY
		Yes		2	
321.5	Drinking alcohol?	No		1	ALCOLDRK
		Yes		2	
321.6	Chewing khat?	No		1	KHATCHEW
		Yes		2	
321.7	Smoking cigarettes?	No		1	SMOKECIG
		Yes		2	
321.8	Anything else?				
322	How severe do you think your child's problem with developing slowly is?	Very severe		1	CHPRB
		Quite severe		2	
		Not too severe		3	
		Not severe at all		4	
323	Who advised you to attend this clinic today (for your child's problems with slow development)?	No one		1	ADVISEDU
		Former patient		2	
		Health worker		3	
		Paediatrician		4	
		Family member		5	
		Friend		6	
		Neighbor		7	
		Religious person		8	
		Traditional healer		9	
		NGO		10	
		Other people		11	
324	Before you came to the clinic today, had you heard of this clinic?	No		1	BEFREHRD
		Yes		2	
325	Do you Believe that child's problems with slow development/autism can be cured? (don't read out responses)	1.Yes, cured		1	DVDCURE
		2.Yes, cured with help of god		2	
		2.Not cured, but improved		3	
		3.No cure or improvement		4	
326	To help your child with slow development to improve, what would help the most?				MOSTHLP

14. DECLARATION FORM

I, the under signed, declared that this is my original work, has never been presented in this or any other University, and that all the resources and materials used for the dissertation, have been fully acknowledged.

Name: _Dejene Tilahun

Signature: _____

Date: _____

Place: Department of Psychatry, School of Medicine, Addis Ababa University

Date of submission: _____

This dissertation has been submitted for examination with my approval as University Supervisor.

Name: Dr. Abebaw Fikadu

Signature: _____

Date: _____