Paper 1

A new measure for excessive parental worries for children's health: Development of The Health Anxiety by Proxy Scale (HAPYS).

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**Abstract** max 250 words (250)

Health anxiety by proxy is a newly introduced term to describe parents’ experience of excessive intrusive and unpleasant worries about their child’s health. These worries may result in increased number of health care contacts and unnecessary physical examinations of the child. This article describes a new measure, the Health Anxiety by Proxy Scale (HAPYS), for systematic assessment of this important clinical phenomenon. The development of the HAPYS was performed according to international guidelines as described by de Vet et al. (2011) over three phases. Phase 1) Patients clinically assessed with health anxiety by proxy participated in semi-structured interviews to elaborate their experience of worries regarding their child's health and their related behaviours, and to examine the face validity of items in an existing questionnaire: "the Illness Worry Scale- parent version". Phase 2) Based on the findings from phase 1 the project group and an international panel of clinical and research experts selected and formulated questionnaire items and corresponding scoring formats. In phase 3) the HAPYS was pilot-tested twice using cognitive interviews with healthy parents and patients with health anxiety by proxy and further adjustments were made. The final version consisted of 26 items covering thoughts, feelings and behaviors characteristic of health anxiety by proxy and an impact section with five items. Based on the pilot testing the HAPYS showed good face and content validity. It holds the potential as a measure which may help clinicians across health care settings to detect and assess parents suffering from health anxiety by proxy.

Keywords: Questionnaire development, assessment tool, health anxiety, parental worries

## ****Introduction****

Parents' excessive worries about their child's health have recently been designated as health anxiety by proxy (Lockhart, 2016). Health anxiety by proxy often coexists with the prevalent disorder health anxiety (classified as hypochondriasis in ICD-11 and Illness anxiety disorder in DSM-5)(American Psychiatric Association, 2016; Thorgaard, Frostholm, Walker et al., 2017b; World Health Organization, 2018). Like health anxiety, health anxiety by proxy is characterized by persistent rumination about health and illness but while patients with health anxiety have fears of suffering from a serious illness themselves (Fink et al., 2004), patients with health anxiety by proxy have intrusive, unpleasant thoughts about their child suffering from a serious illness (Lockhart, 2016). These thoughts may lead to excessive attention directed towards symptoms in their child and a tendency to misinterpret common bodily sensations in the child as signs of illness. As a consequence, the parent with health anxiety by proxy might perform bodily examinations of the child such as observing birthmarks, looking for bruises, or palpating lymph nodes (Lockhart, 2016; Thorgaard, Frostholm, Walker et al., 2017b). Further, this behaviour is likely to increase the child’s number of health care contacts (Little et al., 2001).

According to social learning theory (Bandura, 1986) children primarily learn how to cope with symptoms and illness through reinforcement from and modelling of caregivers (Walker et al., 2006). Several studies have shown that parents’ illness coping strategies and negative illness perceptions can be transferred from the parent to the child (Jamison & Walker, 1992; Köteles, Freyler, Kökönyei, & Bárdos, 2015; Levy, 2011; Marshall, Jones, Ramchandani, Stein, & Bass, 2007; Thorgaard, 2017; Thorgaard, Frostholm, & Rask, 2017; Thorgaard, Frostholm, Walker et al., 2017a; Wright, Reiser, & Delparte, 2017). Thus, exposure to parental maladaptive illness perceptions, behaviours, and worries as seen in health anxiety by proxy may pose a risk factor for later development of maladaptive illness behaviours, perceptions, high health care use and possibly health anxiety, underlining the importance of the detection, assessment and treatment of health anxiety by proxy (Hatcher, Powers, & Richtsmeier, 1993; Janicke, Finney, & Riley, 2001; Little et al., 2001; Richtsmeier & Hatcher, 1994).

Until now, health anxiety by proxy has been a clinical phenomenon largely neglected in paediatric settings (Lockhart, 2016). Thus, no standardized measures for systematic assessment currently exist. However, several instruments exist for measuring health anxiety and hypochondriacal fears in adults (Sirri, 2014), and recently the Fetal Health Anxiety Inventory (FHAI) (Reiser & Wright, 2017) was introduced to assess mothers' health anxiety on behalf of their unborn child. In a recent study we used a preliminary, untested measure, the short questionnaire The Illness Worry Scale – parent version (IWS-p)(Garralda & Rangel, 2001), as a first attempt to measure health anxiety by proxy. Even though the development was brief, it showed promising face and discriminative validity (Thorgaard, Frostholm, Walker et al., 2017b). It may therefore constitute the basis for a systematically developed, detailed and psychometric sound measure of health anxiety by proxy.

This study aims to further develop the IWS-p into a new and extensive measure, the Health Anxiety by Proxy Scale (HAPYS), to assess parents’ excessive worries and anxiety in relation to their child’s health.

## ****Study design****

The development of the HAPYS consisted of three phases covering the first five steps recommended for developing a new measurement tool: a) Definition and elaboration of the construct intended to be measured, b) Choice of measurement method *(Phase 1)*, c) Selecting and formulating items, d) Selecting scoring formats *(Phase 2)*, and e) Pilot-testing *(Phase 3)* (de Vet, Terwee, Mokkink, & Knol, 2011a) (Figure 1). In step b, the choice to develop a self-report questionnaire was predetermined since HAPYS is based on the IWS-p.

**Setting and project group**

The HAPYS was developed at Aarhus University Hospital, Denmark in collaboration between the Department of Child and Adolescent Psychiatry and the Research Clinic for Functional Disorders and Psychosomatics (The Research clinic). The project group consisted of three psychologists (KI, LF, DH) and one child and adolescent psychiatrist (CUR). All psychologists have clinical and research experience with health anxiety in adults, and LF is further specialized in illness perception and psychotherapy. CUR is specialized in functional disorders and health anxiety in children and has previously developed and validated the Soma Assessment Interview (SAI), a parent interview on functional somatic symptoms in children (Rask et al., 2009). The project group collaborated with an international expert panel. The expert panel consisted of two psychologists (KW, MK) and two child and adolescent psychiatrists (EG, EL) with research and/or clinical expertise in paediatric health anxiety and functional disorders, child psychopathology and questionnaire development, respectively. Moreover, KW developed the FHAI (Reiser & Wright, 2017), EG the IWS-p (Garralda & Rangel, 2001) and EL was the first to introduce and describe the term *health anxiety by proxy* in the scientific literature (Lockhart, 2016).

FIGURE 1 HERE

**Methods**

**Phase 1: Definition and elaboration of the construct.**

Phase 1 had two aims: 1) to further conceptualize health anxiety by proxy and define core clinical characteristics of parents with health anxiety by proxy; and 2) to examine the face validity of the items included in the existing measure, the IWS-p, i.e. determine how well it measured health anxiety by proxy.

**Participant recruitment.** Participants for the qualitative interviews were recruited either after diagnostic assessment for health anxiety at the Research clinic or by directing themselves to the project after reading about it at the clinic’s webpage (www.funktionellelidelser.dk). The main author (KI) performed a telephone assessment based on the IWS-p to ensure that all parents with health anxiety by proxy presented significant and excessive worries about their children's health.

**Data collection.** A two-part interview guide was developed in collaboration with the expert panel. The first part was an individual in-depth semi-structured interview (DiCicco-Bloom & Crabtree, 2006) exploring the parents’ lived experience with health anxiety by proxy. The interview encompassed thoughts, feelings, bodily sensations, behaviours, and relationship quality with the child and partner or other family members. The second part was a cognitive interview (World Health Organization, 2019) which investigated the content and face validity of IWS-p with questions about how each item was perceived and how the informants chose their answers (see appendix 1 for full interview guide).

All interviews were performed by the main author (KI) and took place at a location chosen by the participant (primarily their private home or at the research clinic).

**Thematic analysis**. Interpretive phenomenological analysis comprised the theoretical framework for the data analysis of the first part of the interview (Smith & Osborn, 2015). All interview parts were transcribed verbatim using NVivo 12 (QSR International Pty Ltd, 2018) after which the tapes were listened to once again with the transcript as recommended by Thomas and Polio (Thomas & Pollio, 2002).

A thematic analysis was performed to retrieve themes and subthemes (Braun & Clarke, 2006). All interviews were analysed as its own entity; then, they were analysed across interviews. The first analysis was performed separately by two coders (main author, KI, and an external coder (DRH)). DRH is a child and adolescent psychiatrist with qualitative research experience who was blinded to the interview guide. The analysis was discussed until agreement between the two coders was reached. The five remaining interview-analyses were performed by KI supervised by the project group and DRH. Subsequently, the themes were clustered across all interviews, provided with names covering the essence of each theme and agreement on themes was reached with the project group.

All comments on the IWS-p were transcribed verbatim and summarized for each item.

**Phase 2: Formulating items and scoring format**

Phase 2 aimed at formulating the first draft of items and scoring formats for the new measure. The item development and selection process was performed by the project group in close collaboration with the expert panel. Items were based on the identified themes obtained in phase 1 and on items from the IWS-p that received positive feedback, were comprehensible and characteristic of health anxiety by proxy as judged by the parents with health anxiety by proxy. In addition, well-validated questionnaires on health anxiety were used as inspiration for items (Sirri, 2014) and the Strength and difficulties questionnaire (SDQ) inspired the impact section (Goodman, 1997; Goodman, Ford, Richards, Gatward, & Meltzer, 2000; Niclasen et al., 2012). The items were generated in an iterative manner by discussions in the project group and thereafter further with the expert panel (Figure 1).

Response formats from the 8-item Whiteley Index (WI-8) (Fink et al., 1999), the IWS-p (Garralda & Rangel, 2001) and SDQ (Goodman, 1997; Niclasen et al., 2012) were incorporated due to their well-tested response formats and good fit to the different item-wordings in the HAPYS.

**Phase 3: Pilot-testing**

The pilot-testing investigated the content validity as well as the face validity of the HAPYS, i.e. tested the comprehensibility, relevance, completeness, acceptability and feasibility of the included items and corresponding response categories (de Vet, Terwee, Mokkink, & Knol, 2011a). The face and content validity was investigated using cognitive interviews in two separate rounds.

**Participant recruitment**. New parents with health anxiety by proxy for the pilot testing were again recruited from the Research clinic as in Phase 1. Healthy parents were recruited through word of mouth.

**Data collection**. All parents (healthy and with health anxiety by proxy) completed the questionnaire and participated in a cognitive interview about their understanding of each item, the rationale for their responses and about the response formats. Parents clinically assessed with health anxiety by proxy were asked if anything was missing (characteristic of their experience with health anxiety by proxy) and if they recognized their experiences and challenges in the questionnaire (de Vet, Terwee, Mokkink, & Knol, 2011a; Willis, 2005). In the first feedback round one parent with health anxiety by proxy who also participated in phase 1 and four new parents with health anxiety by proxy were interviewed. Three of the four new parents took part in a focus group interview while the remaining two parents provided feedback by telephone. In parallel, nine healthy parents answered the questionnaire and were interview by telephone.

Based on the obtained feedback, the project group and the expert panel modified items in the questionnaire. The modified version was evaluated in a second feedback round over the phone by six parents from the first round (one parent with health anxiety by proxy, five healthy parents). All phone calls were carried out by the main author (KI).

**Results**

**Participant demographics**

In total 19 Danish parents participated in this study (10 parents with health anxiety by proxy and nine healthy parents). Demographics of the parents in the various phases are summarized in table 1. Qualitative interviews were performed with six Danish parents clinically assessed to suffer from health anxiety by proxy. The cognitive interviews were performed with five parents with health anxiety by proxy and nine healthy parents.

TABLE 1 HERE

**Phase 1 - Definition and elaboration of the construct**

**Semi-structured interview.**Six main themes with related subthemes were derived from the interviews: *Ruminative thoughts*, *Negative feelings*, *Control and avoidance behaviour, Impact on quality of life, Previous experience with health* and *Parenting conflicts* (Table 2).

TABLE 2 HERE

**Interview about IWS-p.** Five items in the IWS-p were reused with modifications whereof two items were merged to one, and three items were discharged due to overlap with other items (two items) or irrelevance to health anxiety by proxy (one item) (Table 3).

TABLE 3 HERE

**Phase 2 - Formulation of new items and scoring format**

**Item formulation.** Three of the six main themes; *Ruminative thoughts*, *Negative feelings* and *Control and avoidance behaviour* was used to define separate sections in the questionnaire regarding thoughts, feelings and behaviour, respectively. The themes *Impact on quality of life*, *Previous experience with health* and *Parenting conflicts* inspired the impact section and one further item.

**Selecting scoring formats.** The items in the sections on Emotions and Thoughts employed a Likert-scale with five response categories inspired by the Whiteley-8 index: “Not at all”, “A little”, “Some”, “Quite a lot” and “A lot”. In the section on behaviour we asked the parents to focus on a specific situation in time (“*When my child has symptoms”*) which fitted with the Likert-scale from the IWS-p with five response categories: “Never”, “Rarely”, “Sometimes”, “Often” and “Most of the time”. Lastly, the “Impact” items have a Likert-scale with four response categories: “No”, “Yes, a little bit”, “Yes, quite a bit” and “Yes, a great deal” inspired by the SDQ.

**Feedback from expert panel.**Overall, the face validity of the first draft of the questionnaire was found to be good by the experts. Hence, the HAPYS seemed to cover the characteristic aspects of health anxiety by proxy. However, they provided minor comments on the content, the wording, the instructions and the set-up leading to a few modifications. Among other things, these included changing “*When my child has symptoms*” into “*When I worry about my child’s health”* in the beginning of the Behaviour section and adding “*Social relations”* to the Impact question: “*If yes, does the worries affect your daily life in relation to: Partner or close family; Work or study; Social relations?”.*

**Phase 3 – pilot testing**

**Feedback round 1.** The parents with health anxiety by proxy and healthy parents provided valuable feedback on the questionnaire and directed our attention at items that could be misunderstood. Especially one item was misunderstood by healthy parents: *Reassurance from health professionals about my child’s health only works briefly* (item as after phase 2). The response category ”*Never*” was interpreted as if they never obtained reassurance from health professionals whereas “*Most of the time*” was interpreted as a if they obtained reassurance most of the time. This resulted in a misleadingly high score for healthy parents and made it difficult to differentiate between healthy and anxious parents. The following two items: *I keep my child/children home from day care or school* and *I limit my child/children in various activities (play dates, sports, trips, dates with friends* (items as after phase 2) were also misunderstood by some of the healthy parents where their responses reflected how they would act if their child was really sick and not as actions motivated by anxiety.

Generally, no obvious differences were seen between the healthy parents and the parents with health anxiety by proxy in the behaviour section in this feedback round. According to the healthy parents, this was due to questions reflecting common responses when your child is having symptom complaints (e.g. *I seek information about symptoms and illnesses (online, books, magazines)* or *I seek reassurance from my partner or close family members*) (Items as after phase 2). Also, some of the healthy parents were annoyed because the items were directed at worried parents. In contrast, the parents with health anxiety by proxy found that the items in the questionnaire in general were good and relevant in describing their condition.

In regard to the response category the use of three different response formats was feasible according to the parents. However, the healthy parents had a different understanding of ‘*Often*’. It was interpreted as once every time their child was ill and not as repeatedly or extensively.

**Modification.**According to the feedback described above the behavioural section was changed by adding words indicating quantity and severity (i.e. *I use a lot of time seeking information about symptoms and illnesses (online, books, magazines)* and *I repeatedly seek reassurance from my partner or close family members*). Misunderstood items were modified (e.g. *I only feel shortly reassured, if I seek help from health professionals*) and examples were added to elaborate on the meaning (*I try to distract myself to get rid of the worries (e.g. think about something else, listen to music or watch TV)*).

The expert panel was involved in discussing how to best target both parents with younger and older children. This was particularly relevant in relation to items on behaviour which relevance may depend on age and language development (e.g. asking their child about symptoms and/or checking their child’s body for signs of symptoms). Since this behaviour was interpreted as caused by the same underlying control behaviour this was combined into one item ((*When I worry about my child’s health*) *I keep checking my child’s body for signs of illness and/or keep asking my child about his/her symptoms*).

The expert panel provided suggestions on how to overcome the healthy parents’ misunderstandings of items about limiting behaviour: (*When I worry about my child’s health*) *I keep my child home from day care or school* and (*When I worry about my child’s health*) *I limit my child in various activities (play dates, sports, trips, dates with friends*) (first version). This discussion resulted in a merge of the items and adding a comparison with other parents to stress the excessiveness of the behaviour: (*When I worry about my child’s health*) *I am more inclined than other parents to limit my child in various activities (play dates, sports, school, trips, dates with friends*).

Furthermore, to comply with the healthy parents’ frustration when asked repeatedly about their non-existing worries the following instructions were added in the beginning of the questionnaire: *Please note there are no wrong or right answers, therefore answer each item in terms of how frequently the statement applies to you* (The changes can be seen in appendix 2).

**Feedback round 2.** The adaptations of the behavioural section received good feedback from the healthy parents. They no longer reported high scores after the amendment of *repeatedly* and *a lot of time* to the items. Previously misunderstood items were now transparent and the parent with health anxiety by proxy still found all items relevant for the condition. The final version of the HAPYS questionnaire can be seen in table 4.

TABLE 4 HERE

**Discussion**

**Main results.** The HAPYS is the first systematically developed questionnaire to assess health anxiety by proxy. The 26 item questionnaire covers thoughts, feelings, behaviors and impact of health anxiety by proxy and was systematically developed through three phases with parent and expert involvement. The HAPYS showed good face and content validity based on the pilot-testing with anxious and healthy parents and feedback from the expert panel of health professionals. Thus, the HAPYS seems to 1) adequately reflect health anxiety by proxy, 2) refer to relevant clinical aspects of health anxiety by proxy, and 3) fit different ages of children and various illness characteristics.

The results from the qualitative interviews support the suggested conceptual presentation of health anxiety by proxy in Thorgaard et al. (2017) and Lockhart (2016). However, the themes *Parenting conflicts* and *Previous experience with health* provided us with new perspectives on health anxiety by proxy. These themes included for instance conflicts that arose because the other parent prevented the parent with health anxiety by proxy from performing control behavior like checking the child. Also, all of the parents have had negative experiences with the health care system providing them with a feeling of justified mistrust in health professionals. This is also seen in adults suffering from health anxiety (ref?).

The HAPYS share characteristics with the related questionnaire FHAI measuring the related construct fetal health anxiety (Reiser & Wright, 2017). Persistent worries about ones child’s health, repeated images of ones child being ill, difficulties trusting the doctors’ reassurances and questions about whether family members think the parent worries too much are subjects that echoes in the two questionnaires. The development of the HAPYS also shared similarities with the development of the FHAI. Like HAPYS, the FHAI was developed from an existing questionnaire, though as an adaption of the Short Health Anxiety Inventory (Abramowitz, Deacon, & Valentiner, 2007; Salkovskis, Rimes, Warwick, & Clark, 2002). The adaption process of the FHAI included a review by the target group (here: pregnant women) and by subject matter experts similar to the pilot testing and the expert involvement in the present study. However, this study differed from the FHAI development in conducting qualitative interviews and in only using some items from the IWS-p that were also changed to the parents’ critique. Further, the pilot testing was more extensive in the present study and included both anxious and healthy parents whereas the FHAI study included healthy pregnant women but did not focus specifically on women suffering from fetal health anxiety (Reiser & Wright, 2017).

**Strengths and limitations**. The major strength of this study is the detailed pilot testing of the HAPYS with cognitive interviews. This approach is crucial because it ensures that every item is understood in the way the researcher intended it to and that the items are relevant and exhaustive for the construct to be measured (Collins, 2003). Furthermore, involving healthy parents in the pilot testing contributed significantly to the knowledge about common parental behavior and thus minimized the risk of items being misunderstood. This emphasized the importance of also pilot testing a new assessment tool on laymen with no knowledge about or personal experience with the given condition. In general, expert, patient and public involvement ensures the development of comprehensible, specific, exhaustive and relevant items in questionnaires (de Vet, Terwee, & Mokkink, 2011). Additionally, the parents involved were a fairly heterogenic group with both mothers and fathers in different age ranges and with children spanning in age from below 5 years to adulthood.

According to the guideline used in this study (de Vet, Terwee, Mokkink, & Knol, 2011a), a field test is considered part of the developmental process. A field test aims at item reduction, item response testing and at obtaining insight into the factor structure of the questionnaire (de Vet, Terwee, Mokkink, & Knol, 2011b). The lack of a field test could be considered a limitation in this study. However, a field test requires a large study population of minimum 100 patients, in this case with health anxiety by proxy. Due to the HAPYS being the first instrument to identify patients with health anxiety by proxy we relied on the smaller amount of parents with health anxiety by proxy from the pilot test and on the experts to ensure thoroughly formulated exhaustive, distinctive and specific items. For future psychometric testing of the HAPYS, factor analyses and item response theory would be interesting techniques to use to investigate the structure of the questionnaire. A further limitation is that the parents with health anxiety by proxy in phase 1 and 3 were assessed using the IWS-p and clinical knowledge since no formal assessment instrument yet existed. However, this is a common limitation when developing the first formal assessment tool to measure a phenomenon.

**Clinical implications.** To date, very little research is available on parents’ excessive worries about their children’s health. Only one study has investigated this in a health anxiety population (Thorgaard, Frostholm, Walker et al., 2017b) and additionally, just two studies have investigated parents’ worries when their child has a chronic illness (Bonner et al., 2006; DeVet & Ireys, 1998). The HAPYS may help bring focus to this specific field and identify parental excessive worries about their child’s health in different clinical settings like general practice and specialized treatment settings. This is important as it may prevent transmission of maladaptive illness perception and illness behaviour from parent to child as well as unnecessary child medical visits. Thus, Richtsmeier and Hatcher suggested that worries about the child’s health can be a target for intervention even in short paediatric visits in order to prevent unnecessary visits from anxious parents (Richtsmeier & Hatcher, 1994). Finally, the HAPYS may help to differentiate parents suffering from health anxiety by proxy from those who fabricate or induce illness in their child and who are in need of different treatment approach.

**Conclusion.** In conclusion, the HAPYS assesses distinctive thoughts, feelings and behaviours characteristic for health anxiety by proxy. We believe the HAPYS will be applicable in a wide range of clinical and research settings. Future research should formally validate the HAPYS by investigating its psychometric properties in a larger sample. Accordingly, we are currently conducting a study of the HAPYS’ discriminative validity, convergent validity and test-retest reliability.

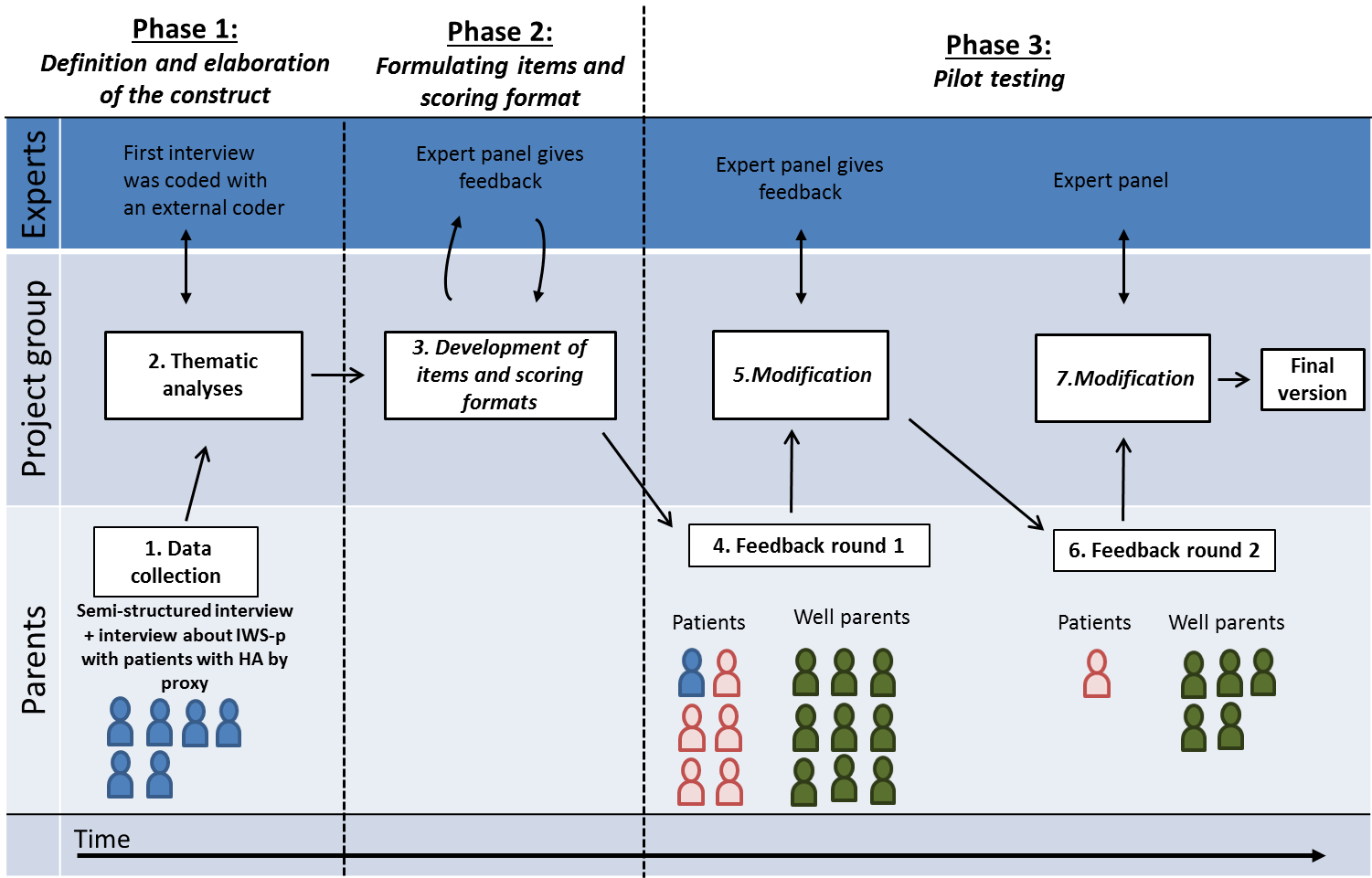
**Acknowledgements**

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**Conflicts of interest**

There were no conflicts of interests.

**Figures and tables**



***Figure 1 - The developmental process of the HAPYS***

The figure illustrates how the HAPYS was developed and who participated in which phases.  = parents with health anxiety by proxy recruited for phase 1 (of whom one also participated in phase two).  = parents with health anxiety by proxy recruited for phase 3.  = healthy parents recruited for phase 3.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| *Table 1 – participant demographics* | | | | | | | |
| Informant | Age range  (gender) | Child age range  (gender) | Civil status | Further  education | Recruitment | | Participation |
| Parents with health anxiety by proxy | | | | | | | |
| 1 | 20-29 (♂) | 0-5 (♂) | Relationship | Medium long (Y) | | c | Phase 1 |
| 2 | 30-39 (♂) | 0-5 (♂) | Relationship | Long (Y) | | c | Phase 1 |
| 3 | 30-39 (♀) | 6-10 (♀) | Relationship | Medium long (Y) | | s | Phase 1 |
| 4 | 40-49 (♂) | 11-15 (♀) | Relationship | Long (Y) | | c | Phase 1 |
| 5 | 50-59 (♀) | 16-20 (♂) | Single | Medium long (N) | | s | Phase 1 |
| 6 | 40-49 (♀) | 16-20 (♂)  16-20 (♂) | Single | Medium long (Y) | | s | Phase 1  Phase 3 |
| 7 | 40-49 (♂) | 0-5 (♀)  6-10 (♀)  6-10 (♀) | Relationship | Short (Y) | | c | Phase 3 |
| 8 | 40-49 (♂) | 21-25 (♀) | Relationship | Long (Y) | | s | Phase 3 |
| 9 | 30-39 (♂) | 0-5 (♂) | Relationship | Short (Y) | | s | Phase 3 |
| 10 | 40-49 (♂) | 11-15 (♀)  16-20 (♂)  21-25 (♀) | Single | Short (Y) | | c | Phase 3 |
| Healthy parents | | | | | | | |
| 11 | 40-49 (♀) | 6-10 (♂)  11-15 (♂)  11-15 (♀) | Relationship | Long (Y) | | - | Phase 3 |
| 12 | 30-39 (♀) | 0-5 (♀)  6-10 (♀) | Relationship | Medium long (Y) | | - | Phase 3 |
| 13 | 40-49 (♂) | 6-10 (♀)  11-15 (♀)  11-15 (♂) | Relationship | Medium long (Y) | | - | Phase 3 |
| 14 | 40-49 (♂) | 6-10 (♂)  11-15 (♂) | Relationship | Long (Y) | | - | Phase 3 |
| 15 | 40-49 (♀) | 11-15 (♂)  15-20 (♀) | Relationship | Long (Y) | | - | Phase 3 |
| 16 | 40-49 (♀) | 6-10 (♂)  11-15 (♀)  11-15 (♂) | Relationship | Long (Y) | | - | Phase 3 |
| 17 | 20-29 (♀) | 0-5 (♂) | Relationship | Long (Y) | | - | Phase 3 |
| 18 | 40-49 (♂) | 6-10 (♂)  11-15 (♀)  11-15 (♂) | Relationship | Medium Long (Y) | | - | Phase 3 |
| 19 | 30-39 (♂) | 0-5 (♀) | Relationship | Long (Y) | | - | Phase 3 |

Age range has been added for anonymization.

Long: > 5 years. Medium long: 2-4 year. Short: < 2 years.

Working: Y= Yes, N= No.

C= clinic, S=self directed.

|  |  |
| --- | --- |
| ***Table 2 – Themes and subthemes*** | |
| **Themes and** subthemes | **Citations** |
| ***Ruminative thoughts*** |  |
| Worries about loosing child |  |
| Worries if the child is ill |  |
| “What is normal worry?“ |  |
| Mistrust in health professionals |  |
| Worries about transmitting health anxiety to child |  |
| Worries about overlooking illness in the child  Inner conflict about protecting child vs. not transmitting health worries |  |
|  |  |
| ***Negative feelings*** |  |
| Sadness |  |
| Guilt, Shame |  |
| Anxiety |  |
| Embarrassment |  |
| Responsibility |  |
| ***Control and avoidance behaviour*** |  |
| Read about illness |  |
| Seek confirmation from close relatives |  |
| Visit or call the doctor |  |
|  |  |
| Examine the child’s body |  |
| Limits the child in activities |  |
| Keep an extra eye on the child |  |
| Avoid to read or hear about ill children |  |
| ***Impact on quality of life*** |  |
| Less attentive and present |  |
| Less able to concentrate |  |
| Meets trouble halfway |  |
| Lacks happiness in activities with the child |  |
| ***Parenting conflicts*** |  |
| Wish to be the perfect parent |  |
| The other parent comforts and reassures |  |
| Conflict with the other parent |  |
| The other parent is in the way of control behaviour |  |
| Lack of trust between the parents |  |
|  |  |
| ***Previous experience with health*** |  |
| Former experience with reason to worry about child’s health. |  |
| Death in close family. |  |
| Own childhood experiences with death and anxiety. |  |
| Other family members with anxiety |  |
| Bad experiences with the health care system. |  |

|  |  |  |
| --- | --- | --- |
| ***Table 3 – Items kept from the IWS-p*** |  |  |
| **IWS-p items** |  | **Argument** |
| 1. I worry about his/her health | **√** | This item was reused as a general statement of worry. |
| 2. The thought that he/she may be seriously ill scares me | **⁄** | Was discharged because ‘scared’ was too strong a word to use and because parents felt that everyone would be scared if their child was seriously ill. |
| 3. If he/she has a pain I worry that it may be caused by serious illness | **√** | This item was perceived by the patients as descriptive of their condition and therefore it was reused with a slightly different wording combining item 3 and item 6. |
| 4. I am afraid he/she may have a serious illness?  - which illness \_\_\_\_\_\_\_\_\_\_\_\_\_\_ | **√** | Because of its emotional description of health anxiety by proxy the item was reused, but without “*which illness*?”. |
| 5. I worry that he/she may get a serious illness in the future | **⁄** | Overlap with IWS-p-item 4 |
| 6. If he/she complaints of feeling a bodily sensation I worry about it | **√** | This was reused in combination with IWS-p-item 3 because pain was perceived as being a bodily sensation. |
| 7. My family/friends would say I worry too much about his/her health | **√** | This item was a good indication of severity and therefore reused |
| 8. Bodily symptoms stop him/her:   * from going to school * from concentrating doing things * from enjoying things | **⁄** | This was not relevant for the parents own anxiety. The parents felt that this was a question for their child to answer. |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| ***Table 4 - The final version of the Health Anxiety by ProxY Scale (HAPYS)*** | | | | | | | | |
| **Parents’ worries about their child’s health**  ***The Health Anxiety by Proxy Scale***  The following statements are about thoughts, feelings and behaviour parents may experience when they are worried about their child’s health. If you have more than one child, we ask you to answer the questionnaire based on the child whose health you may have the most worries about or choose a child at random.  Please note, there are no wrong or right answers, therefore answer each item in terms of how frequently the statement applies to you.  Do not use too much time on the questionnaire, but answer what first come to mind.  Are you the mother or the father of the child?\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Child’s age \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | |
|  | Not at all | A little | | Some | | Quite a lot | | A lot |
| All in all, how much are you worried about your child’s health? | **** | **** | | **** | | **** | | **** |
| ***Thoughts*** |  |  | |  | |  | |  |
| 1. I keep having thoughts about my child’s health | **** | **** | | **** | | **** | | **** |
| 1. It is difficult to put thoughts about my child’s health out of my mind | **** | **** | | **** | | **** | | **** |
| 1. I have thoughts that symptoms like pain, fatigue or discomfort etc. in my child are signs of serious illness | **** | **** | | **** | | **** | | **** |
| 1. People close to me think I worry too much about my child’s health | **** | **** | | **** | | **** | | **** |
| 1. I think I worry more about my child’s health compared to other parents | **** | **** | | **** | | **** | | **** |
| 1. I have intrusive unwanted thoughts that my child is seriously ill | **** | **** | | **** | | **** | | **** |
| 1. I have thoughts that the doctor might be wrong if he/she tells me there is nothing to worry about | **** | **** | | **** | | **** | | **** |
| ***Feelings*** | Not at all | A little | | Some | | Quite a lot | | A lot |
| 1. I am worried that my child could have a serious illness | **** | **** | | **** | | **** | | **** |
| 1. I am worried about passing worries about health on to my child | **** | **** | | **** | | **** | | **** |
| 1. I am worried that I am missing a serious illness in my child | **** | **** | | **** | | **** | | **** |
| 1. I am worried that the doctor is missing a serious illness in my child | **** | **** | | **** | | **** | | **** |
| 1. If I hear or read about illness, I get worried that my child may suffer from the same illness | **** | **** | | **** | | **** | | **** |
| 1. Worrying about my child’s health makes me feel sad | **** | **** | | **** | | **** | | **** |
| 1. I feel guilt or shame because of worries about my child’s health | **** | **** | | **** | | **** | | **** |
| 1. I feel like I am losing control if I worry about my child’s health | **** | **** | | **** | | **** | | **** |
| ***Behaviour***  **When I worry about my child’s health:** |  |  | |  | |  | |  |
|  | Never | Rarely | | Some-times | | Often | | Most of the time |
| 1. I spend a lot of time seeking information about symptoms and illnesses (online, books, magazines) | **** | **** | | **** | | **** | | **** |
| 1. I repeatedly seek reassurance from my partner or close family members | **** | **** | | **** | | **** | | **** |
| 1. I repeatedly seek reassurance from my doctor or other health professionals | **** | **** | | **** | | **** | | **** |
| 1. I only feel briefly reassured, if I seek help from health professionals | **** | **** | | **** | | **** | | **** |
| 1. I keep checking my child’s body for signs of illness and/or keep asking my child about his/her symptoms | **** | **** | | **** | | **** | | **** |
| 1. I feel a need to check my child’s body for signs of illness | **** | **** | | **** | | **** | | **** |
| 1. I am more inclined than other parents to limit my child in various activities (play dates, sports, school, trips, dates with friends) | **** | **** | | **** | | **** | | **** |
| 1. I pay more attention to his/her behaviour | **** | **** | | **** | | **** | | **** |
| 1. I avoid reading or hearing about children’s illnesses | **** | **** | | **** | | **** | | **** |
| 1. I restrict my child's exposure to sick people. | **** | **** | | **** | | **** | | **** |
| 1. I try to distract myself to get rid of the worries (e.g. think about something else, listen to music or watch TV) | **** | **** | | **** | | **** | | **** |
| **Impact** | *No* | | *Yes, a little bit* | | *Yes, quite a bit* | | *Yes, a great deal* | |
| **Overall, do you think that your worries about your child’s health are a problem?** | **** | | **** | | **** | | **** | |
| **If yes**, how long have the worries been present? (circle) | 0-6 months | | 6-12 months | | Over a year | |  | |
| **If yes, do you think the worries are a burden for:** | *No* | | *Yes, a little bit* | | *Yes, quite a bit* | | *Yes, a great deal* | |
| You? | **** | | **** | | **** | | **** | |
| Your child? | **** | | **** | | **** | | **** | |
| Your family as a whole? | **** | | **** | | **** | | **** | |
| **If yes, does the worries affect your daily life in relation to:** | *No* | | *Yes, a little bit* | | *Yes, quite a bit* | | *Yes, a great deal* | |
| Your partner or close family? |  | | **** | | **** | | **** | |
| Work or study? | **** | | **** | | **** | | **** | |
| Social relations? | **** | | **** | | **** | | **** | |
| **Do you know how your worries about your child’s health started?**  Yes No |  | |  | |  | |  | |
| **If yes, describe it here:** |  | |  | |  | |  | |

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