* **Unmet needs in young adults with a parent with a chronic condition: a mixed method investigation and measure development study.**
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* Patterson - Critical revisions for important intellectual content; Subject matter expertise; supervision.
* McDonald - Subject matter expertise; supervision.
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* **ABSTRACT**

Rationale: Given the high number of young adults caring for a family member, and the potential for adverse psychosocial outcomes, there is a need for a screening tool, with clinical utility, to identify those most vulnerable to poor outcomes and to aid targeted interventions.

Objectives: (i) To determine whether current knowledge from cancer literature regarding young carers is generalisable to chronic conditions and, therefore, whether an existing screening tool could be adapted for this population. (ii) To develop a measure of unmet needs in this population and conduct initial psychometric analysis.

Design: This was mixed-methods: interviews in study one informed measure development in study two. Inclusion criteria were: having a parent with a chronic condition, and being aged 16-24 years. In study 1, an interpretative phenomenological analysis was conducted on interviews from seven young adults (age range 17-19 years). Study 2 explored factor structure, reliability and validity of the Offspring Chronic Illness Needs Inventory (OCINI). Participants were 73 females and 34 males (mean ages 18.22, SD = 1.16; 18.65, SD = 1.25).

Main Outcome Measures: OCINI, Depression Anxiety and Stress Scale, and the Adult Carers Quality of Life Scale.

Results: Interviews communicated that the impact of their parent’s condition went unacknowledged and resulted in psychosocial, support and informational needs. An exploratory principal axis analysis of the OCINI yielded five factors. Significant and positive correlations were found between unmet needs and stress, anxiety, and depression, and inversely with quality of life.

Conclusions: The scale has applications in clinical settings where these young people, who are at risk of negative psychological outcomes, may be assessed and unmet needs targeted appropriately.

Keywords: Caregivers; Adult Children; Chronic Disease; Depression; Anxiety; Quality of Life.

**INTRODUCTION**

In the UK there are an estimated 290,000 young adults carers, with 13,000 caring for someone for 50 hours each week [1]. Becker [2] defines young carers as:

Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. (p. 378).

Elsewhere, definitions include individuals up to age 25 [3].

Caring as a young adult may have detrimental effects on physical functioning (e.g., back pain from the physical caregiving duties [4]), education [5], social life [6], sleep, and eating patterns [7]. Young adult carers report poor psychosocial outcomes including; anger, emotional exhaustion, a sense of isolation [8], depression [9], stress [10], and vulnerability to developing psychological problems later in life [11, 12]. We know from the cancer literature that noticeable life changes since parental diagnosis are; increased personal responsibility, and decreased social activity [13], resulting in a loss of childhood.

Stress can be explained as the outcome when perceived individual abilities and resources do not fit environmental demands [14]. Perceiving one’s actual or potential resources and abilities as adequate to address demands, is critical to adaptive psychosocial adjustment to stressful events [15]. Poor health and psychosocial outcomes are associated with perceiving a lack of resources and abilities [16]. Responses to a stressful event are underpinned by assessment of one’s needs in terms of resources, abilities, and on going effort required to acquire or maintain them [17]. As such, it is useful to explore the nature of individual needs in explaining psychosocial responses to demanding events.

Psychosocial needs are defined as ‘…a desire or requirement for help or support that underlies a person’s emotional and psychological wellbeing.’ [18, p1]. Much work has been undertaken in the cancer literature on young carers’ needs. This population report needing information about their parents’ condition; particularly potential survivability [19, 20], and heritability of the condition [20]. Information is suppressed by a parent’s desire to protect their child, and, the reticence of the young carers to ask questions, at risk of mutual upsetting [20].

Young people with parents who are cancer patients express a need to be involved in conversations with medical practitioners and a need for acknowledgement of their family role as a caregiver [21]. Having social recognition of the caregiving role is associated with positive experiences, such as benefit finding [22]. Young cancer carers also report practical needs associated with learning new skills to assist caring for themselves and their parent [13, 23, 24].

This population report a need to express and cope with their own feelings about their parent’s cancer [21, 23]. Recreational timeout from the illness experience may provide young carers with distraction and increased perception of normality [13, 23].

Patterson and colleagues developed the Offspring Cancer Needs Instrument (OCNI) to systematically and objectively measure needs of young people who have a parent with cancer. Using this tool, they reported greater unmet needs were associated with higher reported negative affect [23, 24]. Having this measure is important in developing targeted information and support to help with the caregiving role.

We aim to establish whether these experiences are generalisable to young people with parents who have other conditions, as the OCNI may be adapted for broader use in measuring unmet needs these young people. Chronic conditions are typically noncommunicable, long duration, slow progressing illnesses. This includes, for example, cardiovascular disease, cancers, respiratory disease, and diabetes [25]. Given that 23% of children under 16 live in a family home where someone has a chronic condition [1], the development of this tool is especially important.

With the rising number of individuals being successfully treated for cancer, and remaining in regular contact with medical professionals for a pro-longed follow up period, cancer is recognised as a chronic illness, and interventions for managing cancer as a chronic illness are evolving [26]. It is timely to explore whether experiences of the young person with a parent with a chronic condition, align with those who have parents with cancer, to facilitate as smooth transition towards employing the same interventions, outcome measures, and grouping them together for research purposes.

The aims of this study were:

To determine whether current knowledge from the cancer literature is generalisable to chronic conditions and, therefore, whether an adapted version of the OCNI might be feasible.

To develop a measure of unmet needs in this population (either a revised version of the OCNI, or a new measure) and conduct initial psychometric analysis.

STUDY ONE

Method

*Design.*

To ascertain whether the experiences and unmet needs of young people with parents with a chronic condition were similar to those previously reported by young people with parents who are of cancer patients, we undertook a qualitative study, employing face-to-face, one-to-one, interviews and interpretative phenomenological analysis (IPA)[27]. IPA is widely used in health psychology as demonstrated by Brocki and Weardon’s systematic review [28], and was selected as an ideal framework for analysis due its focus on using participant narratives to understand experiences and the subjective meaning that they conceptualise from them.

*Participants.*

To be included, participants needed to spend at least two days per week, or live permanently, with a parent diagnosed with a chronic condition by a medical practitioner at least three months prior to participation, and be 16-24 years of age. Due to difficulties with identifying young carers, opportunistic sampling was used to recruit seven young adults (2 male, 5 female) from UK colleges (see table 1).

INSERT TABLE 1 ABOUT HERE

*Data Collection.*

Ethical approval was granted by a University Ethics Committee. Potential participants responded to recruitment posters in their college to arrange a one-to-one interview, conducted in a private room at their place of study. After giving informed consent, participants were interviewed for between 30 and 85 minutes. The research team developed an interview schedule (Table 2), informed by the previous literature, and items in the OCNI. Questions were based around a narrative of the parent’s condition, family roles and dynamics, and support. In accordance with IPA guidelines [27], the interview schedule was applied in a flexible manner, each topic was covered, but the sequence was participant-led. Interviews were carried out by an experienced trainee counselling psychologist, and audio recorded. We provided a debrief sheet including information on sources of support. Interviews were transcribed using pseudonyms to protect identity.

INSERT TABLE 2 ABOUT HERE

*Data Analysis.*

IPA is a flexible approach to thematic analysis allowing for double-hermeneutic interpretations to be made by the researcher [29]. Transcripts were read multiple times to allow a thorough understanding of the dataset. Two independent researchers conducted initial analysis using a two-step procedure; first, making summary notes of participant dialogue, and second, extracting thematic labels. The two independent analyses were then developed into an overall thematic framework of super-ordinate themes [30]. Themes were analysed according to theoretically informed interpretation, and sample convergence and divergence of phenomenological experience and conceptual meanings. Our approach to analysis minimised researcher bias and maximised validity and rigour; each stage was verified by at least one member of the team and an audit trail of emergent themes was constructed.

Results and Discussion

The analysis resulted in four super-ordinate themes: The need to be informed, The need to be acknowledged, The need to be supported, and The need to be more than just a carer.

The need to be informed

Being informed, at each stage of the condition, was important to reassure young adults and facilitate their emotional coping: ‘mum told me what it was and I felt so relieved. I cried that night as I was so relieved.’ [Jayne 326-327]. Jayne went on to discuss the importance of this communication, including the entire family coping by ‘coming together’.

 The benefits of being well-informed have been reported extensively [31, 32]. Participants highlighted barriers to accessing the information they needed. Some participants felt that their parents were ‘sheltering’ or ‘protecting’ them; this led the young adults to fear the worst and feel distrust: ‘Why didn’t anyone think about talking to us about all of this stuff, like if we were old enough to care, surely we were old enough to understand? [Kathleen, 465-468].

They sought information from alternative sources: ‘I knew that the leaflets wouldn’t lie or make it sound better than it was. They would be truthful.’ [Julie, 163-165].

Being informed wasn’t sufficient; participants wanted to use information to stimulate further discussion with their ill parent, and generate openness and honesty about their situation [21], but this sometimes caused difficulties with more protective members of family: ‘he’s [the ill father] not interested and mum just got a bit upset, well like pissed off that I was showing it [to] her’ [Jason, 183-185].

Outside of family, participants expressed a need for their wider social network to be informed: ‘I wish that the doctors could have given me something to give my teachers’ [Kathleen, 695-696].

Information was also needed to understand long-term implications of the parent’s condition, and to gain personal control over the otherwise unpredictable nature of their situation: ‘you can prepare yourself or if it’s not going to happen and then you can just relax and not have to worry about it.’[Heather, 143-145]. This was especially where there was a chance of hereditability, in which case information eased fear and embarrassment of having to ask the question themselves: ‘I suppose it would have been good to know what the chances were that I was going to get it’[Julie, 553-554].

The need to be acknowledged

These young adults had taken on either real, or perceived, responsibilities that were outside the ordinary experiences of their peer group; this was sometimes unwelcome. In support of previous research [9], participants expressed a need for acknowledgement of their role in their parent’s condition by others. For Jayne and Julie, a perceived lack of recognition led to feelings of anger and disappointment towards their wider family unit: ‘They ignore me. They think I’m selfish. But I try not to worry them by them feeling guilty at all the stuff I’m doing and the way its ruining, ruling my life.’ [Jayne, 373-375]. ‘I did and do all this stuff to help and at times I wondered if they really knew that I needed help.’ [Julie, 483-485]

Individuation is an important developmental task which is fluid throughout the lifespan yet is crucial during adolescent development [33, 34]; this may be hampered when a family member has a chronic condition [35], as the young person’s parentification acts as a barrier to their self identification [36]. Disruption of this identity process could impact upon the individual’s self concept and expectations from others, thus creating intrapersonal and interpersonal discord [37], such as that described by Jayne and Julie.

The participants don’t see themselves as caregivers; their role is ambiguous, making it difficult for wider social groups to acknowledge their experience: ‘There really should be something to help carers, but I er, suppose like er, I’m not a carer, I’m just looking after Mum’ [Kathleen, 866-868].

These participants were caring for parents in a secretive way – ‘it’s like we don’t exist’ [Carly, 744-747] – and that what they do for their parent is often hidden: ‘I don’t really ever say that I’ve done it, it just, it’s just, like done’ [Jayne, 206-208]. This takes an emotional toll; Carly recognised that she had to work very hard to maintain this controlled façade and to ‘…make it look as though I’m not stressed.’ [Carly, 643-644]. This provides an additional stressor; secret keeping and subject avoidance have been found to have an adverse effect on relationships [38, 39].

The need to be supported

It was challenging for these young adults to seek support from within their own family, they were not only caring for their ill parent, but taking on the challenging role of caring for and protecting the entire family: ‘there were times when I wouldn’t tell dad [the well parent] how bad she [the ill mother] was in case he left us’ [Carly, 292-293].

This need to protect other family members became a bigger concern as these participants grew up and desired their own independence: ‘I know my sister could not take the pressure as well as I can...er, yeah, that’s another worry about moving away to University’ [Kathleen, 166-168].

These young adults are at a crucial stage of their development, where the peer-group are an essential component of their support network, but their responsibilities left little time to socialise with their peers. Participants felt isolated, for example:

‘kinda lonely, like we are the only ones in the world’ [Kathleen, 488]

‘It’s like I’m living a different life to everyone else’ [Jayne, 147-148]

They were misunderstood by their friends: ‘I’m not going out with my friends now coz they’ve got pissed off with me cancelling or having to leave early’ [Jayne, 387-389]. Having peer contact was not just about being supported, it was also about having emotional respite away from their caring responsibility. ‘…it was nice to er get away from it all. But for people to not like make me do really outgoing stuff, just like chilled stuff, like go ice skating, that was always good’ [Heather, 172-175]

Both Jayne and Kathleen explain their lack of peer support as originating from their own peers’ perceptions of the parental condition as being less serious when compared with cancer: ‘if she had something that sounded more scary, I mean I’m glad that she, ya know, I’m grateful, ya know that she doesn’t, I’m sure people would be rallying around’[Kathleen, 231-234].

when I said, like to my friends, that mum might have cancer they were all over me, like so protective and supportive...but when I told them she didn’t have it, they were, like they were really pleased, but they thought that meant that what she has was just like a cold and she’d get over it, but she won’t. [Jayne, 214-221]

If peers do not understand the impact and consequence of the type of condition the parents have, it explains why they were not sufficiently able to support and comprehend our participants’ needs. Jayne turned to her teachers and received a positive response: ‘She was really nice to me and said I could go to her at any time I needed to’ [Jayne, 532-533].

Some young carers sought professional input from counselling services, but where this was not readily available, the problem was compounded:

She [GP] said that she could arrange for me to talk to someone, bit like you I suppose...but when I got the letter it said there was a twelve week wait, so I thought that actually no one is really that interested [Carly, 386-391]

The need to be more than just a carer.

Supporting a parent with a chronic condition is psychologically and emotionally demanding; participants described some profound emotional challenges:

‘I do cry about it’ [Carly, 353]

 ‘I’m not upset really I’m angry’ [Jayne, 385]

 ‘It’s like at times, I feel like I’m her mum’ [Carly, 320-321]

A common theme was the need for respite, to allow themselves to be a young adult without these unexpected responsibilities. For some participants, this was about leaving the home environment: ‘if this was a film someone would come along and sweep me off my feet’ [Jayne, 162-164], ‘I just wanted to escape and be by myself’[Paul, 160-161]. For others it was about withdrawing to comfort and safety: ‘times when I wish I could have been wrapped in a duvet and sat in front of the fire to watch a movie. Like to just be comforted and snuggled up all safely’ [Julie, 459-461]

Finding opportunity to detach from the caregiving role was problematic; there was sustained pressure to be prepared, due to the uncertain nature of chronic illness:

It’s weird coz when he’s not ill all I do is look and wait for him to be poorly then when he is ill, all I want to do is like see what he’s like then get some space to er just chillax. [Heather, 326-329]

Julie reflected on how she would feel if she wasn’t there to provide care: ‘I did wonder ya know, that if something went wrong would it be because I had done something wrong, or forgotten to do something’ [Julie, 346-349]. The young adults felt conflict between their need for time out, and the emotional and psychological consequences of this: ‘more for my peace of mind that I stay at home’ [Kathleen, 158].

Participants reflected on their own health in the future; they clearly worried about being a burden upon someone else and their experiences of being a young carer had led them to be more health-aware: ‘I’m just scared that I’m going to turn into mum, like get poorly and moody’ [Carly, 439-440]

I had really good er stamina and str...strength and to keep my body fat down. So I run to make sure I keep my body fat low and that I feel fit. It’s made a huge difference to how I feel. [Jason, 36-40]

Study Evaluation and Conclusions

Consistent with the cancer literature, the young adults expressed that the complex issues associated with caring, and the impact of the illness upon their life went unacknowledged and gave rise to a number of psychosocial, support and informational needs. One difference is that our participants felt there was more general understanding about cancer, the severity of cancer, and the impact of this on the children of cancer patients, whereas there was much less understanding and therefore less support for other conditions.

The participants represented a wide range of parental chronic conditions. The sample was homogenous in identifying as an informal caregiver for their ill parent and though we attempted to draw on convergence and diverge of experience, there was actually very little difference in the participants’ reports, even with regard to time since diagnosis. Mapping the unmet needs onto the previous literature was beneficial in that it allowed us to identify that the topics that these young people wanted to discuss were comparable to those reported by young people of parents with cancer. From this pilot qualitative work, it was concluded that the OCNI could be adapted and tested for suitability to measure unmet needs for young people who have parents with a chronic condition.

STUDY TWO

Study 2 aimed to test the reliability and validity of the modified OCNI to measure unmet needs in young adults who have a parent with a chronic condition.

Method

Participants.

The same inclusion criteria were applied as for study one. Of the 170 questionnaires distributed, 107 (63%) were returned from 73 females (age 18.22, SD =1.16) and 34 males (age 18.65, SD =1.25). Sample characteristics are in table 3. With regards to sample size required for principal axis factor (PAF) analysis, previous guidance is inconsistent [40-43]. Recently, statistical modelling has been applied to predict accuracy of PAF analysis with given sample sizes. Rouquette and Falissard [44] found that analysis was 96.9% accurate with respect to items loading on the expected factor, where a sample size of 100 was to be used to analyse 45 items; this was therefore used as a guide. Power analysis based on reported correlation between depression and unmet needs [45] indicated that the sample size was adequate for planned correlational analyses.

INSERT TABLE 3 ABOUT HERE

Measures.

The 46[[1]](#footnote-1) items from the OCNI [23, 24] were modified substituting ‘chronic ill health’ or ‘illness’ in place of cancer. For example: ‘Assistance with looking after my parent with cancer’ was altered to read; ‘Assistance with looking after my parent’. Participants responded on a four-point labelled Likert scale, ranging from ‘No need’ to ‘Strong Need’. Quality of life was measured using the Adult-Carers Quality of Life Scale (AC-QoL) [46]. Although not designed specifically for young adults, the measure was developed across a broad age range (19-93 years), and was therefore assessed as suitable. Participants respond on a four-point Likert scale, ranging from ‘Never’ to ‘Always’. The global score was used. Psychological outcomes were measured using the Depression, Anxiety, and Stress Scale (DASS-21) [47] to allow for comparisons with the original OCNI [45]. Participants respond on a four-point Likert scale with responses ranging from ‘Did not apply to me at all’ to ‘Applied to me very much, or most of the time’. Participants completed a demographics form including information about their parents’ condition, and time since diagnosis.

*Data Collection*.

Ethical approval was granted by a University Ethics Committee. Questionnaire packs were distributed through nine UK charity groups and private health centres. Completed questionnaires were returned to the researcher in provided stamped addressed envelopes.

*Data Analysis*.

Data were analysed using the Statistical Package for the Social Sciences. An exploratory principal axis factor analysis was conducted on the OCINI (n=107). A Monte Carlo simulation for Eigenvalues based on the parallel method [48] indicated that the solution from analysis of the real data explained no more variance than the randomly generated solution beyond a five-factor solution. The empirically obtained Eigenvalue for factor five was 2.11, whereas the randomly generated Eigenvalue was 2.01 (see table 4). We applied an oblique method of rotation (direct oblimin) as subscales would all measure unmet needs and were expected to inter-correlate. For this sample size, factor loadings of .5 or greater are deemed statistically significant; only these loadings were retained [49].

We aimed to shorten the measure without losing reliability and validity of subscales. For item reduction purposes, any redundant items were removed iteratively, until removal of an item resulted in a lower internal consistency of the subscale. We used mean inter-item correlations to determine item redundancy, due to the sensitivity of Cronbach’s alpha to the number of items [50].

A lower bound of three items per factor was set to ensure sufficient over-determination [51]. It was of interest to make a comparison between extracted factors and subscales proposed by Patterson et al [23]. Finally, correlations between new subscales and outcome variables were explored.

Results

*Principal Axis Factoring*.

The final factor structure (see table 4) accounted for 70.2 % of variance. Assumptions of sphericity (χ² = 6191.19; p<0.001) and sampling adequacy were met. Five items did not meet criterion for statistical significance and were removed from the scale.

Eight items in factor one were all associated with elements of home life: either tasks, or relationships with the parents. This factor was, therefore, labelled ‘Homelife’ (Cronbach α = .947, mean inter-item correlation =.692). In relation to the OCNI subscales, Homelife comprised items from the ‘Feelings’ and ‘Practical’ subscales and one item from the ‘Time Out’ subscale.

Six items were retained factor two and were associated with the need to seek out information; this scale was, therefore, labelled ‘Information’ (Cronbach’s α = .932, mean inter-item correlation = .713). With respect to the OCNI subscales, this new subscale comprised items from the ‘Information’, ‘Practical’ and ‘Family’ subscales.

The third factor comprised three items. Although one item was marginally below the threshold for significance, it was retained, as it was theoretically meaningful. The reliability (Cronbach α = .785) and internal consistency (mean inter-item correlation = .558) of this subscale were robust. The OCNI subscales of ‘Family’, ‘Support from Friends’, and ‘Feelings’ were all incorporated in factor 3, items were associated with talking, therefore the subscale was labelled ‘Communication’.

Six items were retained in factor four with acceptable reliability (Cronbach α = .918) and internal consistency (mean inter-item correlation = .676). Within this factor, items from the OCNI subscales of ‘Support from Friends’ and ‘Feelings’ were included. This factor was labelled ‘Support from Outside the Family’.

Factor 5 comprised 3 items. The reliability (Cronbach α = .731) and internal consistency (mean inter-item correlation = .473) of this subscale were robust. Items from the OCNI subscales of ‘Family’, ‘Support from Other Young People’ and ‘Feelings’ were included. Items were associated with expressing feeling and being able to talk openly, the subscale was labelled ‘Express Emotion’.

 The process of item reduction resulted in five subscales, and a shorter 26-item measure. Table 4 shows the factor loadings for the retained items, including an indication of which subscale they originated from on the OCNI.

INSERT TABLE 4 ABOUT HERE

*Correlations.*

All five subscales correlated inversely with quality of life, and time since diagnosis, and positively with stress, anxiety, and depression suggesting that higher reported needs were associated with poorer psychological outcomes (see table 5) and a shorter time since diagnosis.

INSERT TABLE 5 ABOUT HERE

Study Evaluation & Conclusions

We developed a short instrument with acceptable reliability and validity, to measure unmet needs in young people who have parents with a chronic condition. Items from the original OCNI, when adapted to chronic condition experiences, are suitable to explore needs in this population. The resultant subscales correlate in the expected direction with psychological outcomes, and patterns are similar to correlations reported by Patterson, et al [24], suggesting construct validity of subscales. A shorter time since diagnosis was associated with higher reported unmet needs.

This initial validation was conducted in the UK, whilst the original work for the OCNI was conducted with an Australian sample: though it is unlikely that cultural differences would account for the differing factor structures, this is perhaps worthy of further attention. As sociocultural data were not central to our study aim, we did not collect this, due to the concern for participant fatigue, in an already burdened group. It would also be valuable, to conduct confirmatory factor analysis with data from young people with parents who are cancer patients to see if this factor structure bears out.

OVERALL DISCUSSION AND SUMMARY

This paper describes a mixed method development of an instrument for measuring unmet needs in young adults with parents with a chronic condition. Using mixed methods provided the advantage of ensuring that the screening tool was relevant to the target population, and addressed a clinical need identified by them. In this way, the mixed methods approach has added breadth and depth to our understanding of the lived experience, and has afforded practical solutions that are feasible and acceptable to the target group [52, 53]. Consistent with the literature (e.g., 11), caring for a parent with a chronic condition had profound emotional and practical implications for family life and individual development. There was a perceived lack of acknowledgement from others of their own caregiving role, and a need for more information about their role and their parent’s health. The reported unmet needs of participants who were interviewed were consistent with the literature describing needs of a young person of a parent with cancer, thus the OCNI was modified, substituting chronic illness in place of references to cancer.

Study two presents initial validation of a modified tool to measure unmet needs in young adults with a parent with a chronic condition. This analysis confirmed the appropriateness of using the modified OCNI for young people with a parent with a chronic condition, and may indicate the potential utility of this tool for further modifications for specific target groups.

The resultant tool has fewer subscales than the original OCNI, and although subscales remain largely representative of the same themes, the items cluster differently. The new factor structure clearly maps onto experiences as seen in the interviews in study one. The different factor structure, when compared to the OCNI, may reflect the subtle variation in the experiences and priorities due to age. The present sample were aged over 17, whereas those who participated in the development of the OCNI were as young as 12.

Though requiring further confirmatory development, this measure has potential as a screening tool in clinical settings and has clear implications for practice. There is good precedent in the cancer literature that health care professionals can easily and effectively screen for needs and use this as a clinical tool to improve communication with carers about psychosocial care (24); in itself the screening can be an intervention. We identified some particular areas of highly prevalent need, such as information. However, as needs assessment is hugely individual, it is inappropriate to change entire services on the basis of these findings alone. Conceptualising and objectively measuring the experiences of young adults with parents with a chronic condition (in terms of their unmet needs) may provide a useful framework for determining content of supportive care services for this group; ensuring that diversity of needs are met.

In support of theory (e.g. 16, 17) unmet needs measured by this new tool significantly correlated with anxiety, stress, depression and quality of life, so interventions to address needs may have significant benefit to this substantial population of young adults. In contrast to study one, we observed an association between time since diagnosis and unmet needs in study two; those reporting more unmet needs were children of parents who were more recently diagnosed. This suggests that the initial adjustment to diagnosis is one critical period that warrants clinical attention. Whilst diagnosis is the key ‘risk’ period of needs, the theoretical literature on stress (e.g. 16, 17) would suggest that any changes in the health of the parent will prompt the young person to appraise their capacity to cope. Hence there could also be later ‘risk’ times too, and assessment at key points would be informative. Future research is needed on these aspects of implementation including the identification of specific clusters of needs for different demographic groups allowing for effective development of supportive care services.

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1. At the time of starting this study, work on validating the OCNI was ongoing. The later published version of the OCNI included one additional item that was not included in the scale for this study: ‘Assistance with how to budget money’, [↑](#footnote-ref-1)