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## “Surviving not thriving”: experiences of health among young people with a lived experience in out-of-home care

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### ABSTRACT

Children in care (CiC) experience poorer health outcomes than their same-aged peers without an experience of care. Despite growing recognition of the importance of listening to the voices of children and young people (YP), to date, the voices of CiC are not well represented in research examining their health. This study aimed to explore the experiences and perceptions of health among YP who have previously lived in care. A co-design approach was used to inform the research methodology by engaging YP with a lived experience in cooperative discussions. Ten YP participated in one-on-one semi-structured interviews and thematic analysis was used to analyse the data. The current findings highlight that YP consistently felt their health needs were not adequately met while in care, nor did they feel listened to, understood, or educated about health-related matters. This unique insight into the challenges they experienced in care offers realistic guidance for change.

### ARTICLE HISTORY

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### KEYWORDS

Children in care; out-of-home care; looked after children; health needs; healthcare; voice

In Australia, out-of-home care (OoHC) includes the provision of short, medium or long-term accommodation for children and young people aged between 0–18 years (henceforth referred to as young people [YP]), who are unable to live with their parents, commonly due to abuse and/or neglect (Australian Institute of Health and Welfare, 2018; Department of Education and Training [DET], 2018). This may include foster care, residential care, kinship care or other types of statutory, public or alternate care.<sup>1</sup> YP living in OoHC often experience higher rates of physical, developmental, behavioural or emotional health problems, and require more health-related services compared to their peers (Chambers et al., 2010; Crawford, 2006; Moeller-Saxone et al., 2016; Nathanson & Tzioumi, 2007; Ward et al., 2002; Webster et al., 2012; Williams et al., 2001). Furthermore, YP are at risk of ongoing health concerns throughout their lifespan (Conn et al., 2015; Kools et al., 2009). It is important to understand the health and subsequent healthcare needs early in the lives of YP in OoHC to prevent poor outcomes during adulthood (Norman et al., 2012).

A growing body of evidence suggests that YP have valuable viewpoints about healthcare, and the voices of YP should be included in research and policy (Bessell, 2011; Grace et al., 2018; McGinnity, 2007). YP can contribute both unique and holistic insights into the challenges they experience while in OoHC, and realistic guidance for change (McGinnity, 2007). To date, the voices of YP in OoHC are not well represented in research examining their health status and/or health needs (Smales et al., 2020). While some academics have attempted to incorporate the ‘lived experience’ in data collection, the research often falls short as the study designs are ineffective in gathering in-depth perceptions, do not consult YP about qualitative research designs or the development of health interventions,

and fail to acknowledge YP's voices holding the same, if not more, weight as the experiences of professionals (i.e., carers and/or health professionals) (Callaghan et al., 2004; McGinnity, 2007).

YP in OoHC have emphasized how the right to be heard and taken seriously is important to their feelings of self-worth (Monson et al., 2019), and that common measures of child health fail to capture their additional and unique concerns (for example, being disconnected from their health history) (Marsh & Selwyn, 2017). The reality of ever-changing carers, case managers, care placements and health practitioners who are all responsible for the health of young people means that the voice of YP as experts in their own lives is critical and necessary (Tregeagle & Hamil, 2011). Consequently, the inclusion of these voices in health research is a vital part of understanding and subsequently addressing possible barriers YP face to improving their health outcomes. YP can provide great insight into the challenges in delivering high quality health care provision for this population that would otherwise not arise from studies only examining the perspectives of case managers, carers, clinicians, and other stakeholders. The overall aim of this study was to engage YP who have previously lived in OoHC to share their perceptions and experiences of the health care system and to gain insight into their perceived health needs and their participation in health care planning.

## Method

### *The researcher*

The first author, lived in a residential care unit and other forms of care for four years from the ages of 14–17, and has had ongoing experience working within the OoHC system. The senior (last named) author spent one year working in residential OoHC. These experiences and knowledge of OoHC helped to inform the researcher's approach to the study, including the research design, methodology, analysis of data, and overall interpretation and reporting of the results. This circumstance is not uncommon in research (Hodkinson, 2006; Taylor, 2011). This approach, commonly known as 'insider research', is where the researcher intentionally and purposefully positions themselves in their research to utilize their shared experiences and understandings of the phenomena to better explain or explore the research topic (Wilkinson & Kitinger, 2013). The researchers had identified significant gaps in the literature that were noticeable because of their personal experiences and knowledge. Using researchers with a lived experience of the OoHC system helped guide the development of an appropriate study methodology and potential interview questions. This was bolstered by seeking further guidance and confirmation of the study appropriateness from consultations with YP with a lived experience (as outlined below). The researcher's 'insider' perspective also offered the advantage of being able to identify with the participants in a way that other researchers might not have been able to, giving them the ability to see, understand, and interpret deeper meanings or contexts to the participants' responses. The shared experiences between the researchers and participants gave them an insight or understanding of the data that may have gone unnoticed by other researchers, potentially leading to more reliable data interpretation. All ethical, moral and professional processes were followed to minimize any possible biases in the reporting of results.

### *Sampling*

Ethics was approved by the University's Human Research Ethics Committee. The sample included individuals with a lived experience of OoHC (i.e. kinship, foster, and/or residential care, and other forms of alternative care) who were 18 years of age or older and able to provide informed consent. Purposive sampling was used to recruit via two methods: (1) through a liaison contact [from a Victorian community service organization] who identified possible YP that met the participant recruitment criteria; and (2) a recruitment flyer posted via social media platforms (e.g., Facebook). A total of 10 YP (five males and five females) participated in the research; their age range was 18 to 27 years. Six YP had a previous care experience in residential care, five had lived in kinship care, four in foster care, and three YP had previously

lived in alternative care placements. The participants were not able to recall how long, overall, they had spent in care. Two participants had a support person sit in on their interview – any comments from non-participants were excluded from analyses. After providing consent, one additional female participant was unable to book a suitable interview time and did not participate in the study.

### **Data collection**

To ensure integrity in encompassing the voice of YP and truly exploring and addressing topics that were deemed important by the YP (rather than imposing the researcher's predetermined ideas of what was of importance), the study protocol was co-designed and developed in consultation with a group of YP. This group comprised of three females and one male with a lived experience of OoHC who were sourced from a Victorian community service organization. Feedback was sought on: (1) the relevance and appropriateness of the overall study design; (2) the structure and design of the study participant materials, including recruitment flyers, the explanatory statements, and consent forms; and (3) the semi-structured interview schedule. Semi-structured interviews were conducted with each of the participants. This approach allowed the researcher to provide prompts and ask for clarification or elaboration where necessary. Interviews were conducted by a female student researcher (author MS), and two female post-doctoral research fellows (authors RG and LB), trained in qualitative methodologies. Three interviews were conducted face-to-face (participants requested that their interview take place in a public area such as a library), and the remaining seven participants completed a phone interview; participants were not known to the interviewer. The interviews ran for 30–90 minutes in duration and all interviews were audio recorded with the participants' consent to be later transcribed by a third-party transcription service for qualitative analysis. Field notes were taken during the interview and later compared to each interview transcription. Due to time constraints during the data collection period, transcripts were not returned to participants for comment nor were they asked to provide feedback on the findings. All participants received a 50 AUD gift voucher for their participation. Data saturation was met after 10 interviews were completed. At this point, no new themes or concepts were being uncovered, suggesting it was an appropriate time to stop data collection.

### **Data analysis**

A descriptive phenomenological approach to analysis was taken (Cresswell et al., 2007) in order to allow for in-depth exploration of YP's experience of: past and present health issues; interactions with health professions; accessing health services; carer and/or worker support in health care; and the processes involved in accessing and/or receiving health care. Each transcript was double-coded in NVivo (qualitative data analysis software, version 12 (2018), QSR International Pty Ltd), independently, by two researchers (MS, RG) and the most common and recurrent codes were grouped together to create overarching themes. The remaining relevant codes were clustered together as potential sub-themes for each main theme. A third research fellow (HM), that was external to all other processes of the study, also coded the data at this point in the study. Codes, themes, and sub-themes were cross-checked to ensure research integrity and prevent any researcher bias. This cross-checking confirmed 100% consistency across the findings of the data and resulted in no changes in themes or sub-themes.

### **Reporting**

This paper was written following the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007) which is available in the supplementary materials, see Table 1.

### **Results**

Four major themes emerged from the interviews with YP: (1) Young people's experience of care does not align with the definition of care; (2) The system lets young people down; (3) Our voices matter;

and (4) Carers need support to better meet young peoples' health needs. Within these major themes, 14 subthemes and supporting quotes were identified. Quotes are verbatim comments from participants, with the exception of the removal of colloquial language, such as 'um'. Additional quotes corresponding to subthemes are provided in the supplementary materials, see [Table 2](#).

### ***Young people's experience of care does not align with the definition of care***

When reflecting on how their health was managed during their time in care, the ten young people interviewed, generally felt that their carers managed their health as a part of the carer or job role, rather than having genuine concern for the young person's wellbeing. For residential care, participants spoke about 'workers' being upfront with them about the rigid boundaries of their role. This is reflected in the subthemes: a) Ticking boxes; (b) It's just a job; and (c) System requirements impact the experience of being cared for.

#### ***Ticking boxes***

When asked about their experience of health while in care, YP largely acknowledged that they were able to see a general practitioner (GP) when they needed to or asked to. Especially in the context of residential care, requests to see the doctor were typically honoured. However, this was interpreted as a requirement of the carer role as opposed to genuine concern over the young person's health.

*... if something came up, I was more likely to get help. So, yes, when I was in a fight and injured my hand, it was straight away, let's go to the doctors that night ... You'd get people saying, if you're sick let us know. But apart from that, there wasn't much conversation around any sort of health. [YP01]*

Most YP, across all care types, reported that they had a care and placement plan<sup>2</sup> and/or described completing various health assessments during their time in care. Some were the exception, stating, "No, I didn't have one" [YP04]. For those who knew they had a care and placement plan in place, many YP admitted that they were unsure of the content of this plan:

*I had heard it mentioned once or twice, I think. But I didn't know about it. I didn't know what it was. [YP07]*

Beyond seeing a doctor for their immediate needs, it was clear that follow-up appointments or ongoing health care was not a routine part of care. When specifically prompted about whether they were given a follow-up plan on any health-related matters after visiting a doctor or health professional, participants described this as uncommon, lacking, or non-existent. YP perceived this as something that was not clearly defined as a requirement of the carer(s) role and therefore was not prioritized. This was acutely evident in the life of this young person:

*I was attacked at school and I had my nose knocked out of place. Blood was pouring all over the place and I got taken to the doctors. They had a look at it. Like slightly checked and said, "oh, it should be okay". But you should follow up, get x-rays. X-rays were never done. [I've had] issues with back pain. A paediatrician said I may have scoliosis, and that needs to be followed up on with my next appointment with them. And then that never happened. I went into care and dislocated my knee. A month or so later, had an ultrasound on it, which never got taken back to the doctors to hear the results of that. [YP07]*

#### ***It's just a job***

While the majority of YP could describe a carer who they felt connected to and would go 'above and beyond' to meet their health needs, most carers were described as just fulfilling their job role, and overall, YP felt that carers did the bare minimum when it came to addressing their health needs. Particularly from the perspectives of YP in residential care, carers were generally viewed as fulfilling a job role rather than perceived as pseudo parents. This is reflected in the language used to describe carers as YP frequently referred to them as 'workers' and described the high turnover of staff during their time in care – this included (Department of Health and Human Services [DHHS]) case managers and social workers. Indeed, most participants reported having too many 'workers' to count. The YP felt this impacted their willingness

to form relationships with their carers and other 'workers', and often left them feeling uncared for. This left one young person to conclude about all children in care: *'We have a real sense that they're just not going to care, they're not going to bother'* [YP04]. Another mimicked this sentiment: *'They don't care about my mental health. They just want to make sure that all the boxes are ticked and the programmes are still getting their funding. Department workers don't care.'* [YP10]

### **System requirements impact the experience of being cared for**

YP felt that requirements bestowed on carers impact their ability to care for the YP in a meaningful way. More specifically, the systems and processes created either by government or non-government agencies, restrict carers from being able to act as 'a good parent would', especially when trying to address a young person's health needs. Examples of this include, recording daily interactions with the YP through case notes, filling out paperwork to acquire parental/guardian consent for healthcare, and policy guidelines restricting carers from discussing particular sensitive health topics with the YP, such as sexual health.

*I don't think anyone asked me about my health at all, to be perfectly honest. I think it was just communication through case notes.* [YP01]

Policies and funding restrictions were also described as limiting 'healthy' behaviours like sports participation:

*I couldn't do martial arts. I wanted to do Muay Thai or kickboxing when I was younger, but I wasn't allowed to because even though I'd never assaulted anyone, I had zero charges, I wasn't allowed to in case I assaulted staff.* [YP10]

The issue of funding arose for another young person in foster care:

*I was involved in athletics and I always loved sport in school. But, after going into that foster care placement, it was, "we can't afford to do that". "You can't do that." "You can't continue with the activity you did before". And so, I just didn't.* [YP01]

Finally, the mandated requirement to develop care and placement plans (especially in relation to health) were haphazardly implemented for the young people interviewed.

### **The system lets young people down**

There was overwhelming recognition among the YP that the OoHC system was not supportive or nurturing enough to foster improved health outcomes during their time in care. Within this second major theme, five sub-themes were identified: (a) Young people grow out of the system; (b) Lack of care/support; (c) Lack of education; (d) Reactive versus active; and (e) Low expectations.

#### **Young people grow out of the system**

Participants talked about the challenge of ageing out of the OoHC system and moving into independent living and described experiences that were unique to YP living in care. YP noted that as they age out of care at 18 years, they face a range of different health setbacks, such as lacking official identification or medical documents that are required to access health services or having to organize health care appointments on their own with little help or education. These factors were viewed as barriers to YP accessing appropriate healthcare services once they had transitioned from OoHC. YP identified that these situations would not typically occur for YP who were raised in the care of their parents.

*... it was incredibly hard, because I had nothing from the unit. I didn't have a birth certificate. I had no identity whatsoever. I didn't even have access to my own bank account because one of the workers who had set it up had left. It was in my name for them to access it and I was 16.* [YP07]

After leaving care, some YP had successfully obtained their case files from the DHHS, however, many said that there was little to no information about their health in these files, *'I have seen no medical stuff in there. Just data reports and incidents notes'* [YP07]. For this young person, there were physical ramifications to reporting failures:

*They were never properly recorded, whether I had shots [vaccinations] or not. So, every year, at high school, when we had shots being done, I got chicken pox every year. Even though I said I had had it the previous year. But there was no actual record of it happening. [YP07]*

### **Lack of care/support**

YP reported feeling unsupported by their carers/workers due to the nature of the OoHC system, including the instability of their placement and not receiving support (i.e., contact) by case managers. YP described specific times where they were unable to voice their health concerns to workers/carers or times where their workers/carers were absent or unable to attend to them during an occasion of poor health (i.e., feeling physically unwell). Participants also spoke about times when they did have access to carers to speak about their mental health concerns but reported that carers often dismissed or minimized these concerns (i.e., 'you are fine') or did not adequately address their concerns (i.e., no follow-up, no support provided, no referral to relevant health services).

*When I was about 16 I attempted [suicide] and was put into a mental health unit for about a month and a half ... they just put me in there and they didn't really come and visit. They didn't stop by and check up on me. I got home and everything just went straight back to normal. [YP08]*

*I didn't feel understood by carers. I didn't want to get help because the people I would have to share this with to be able to get help wouldn't be able to understand or relate to what I was experiencing. [YP04]*

### **Lack of education**

YP noted that they did not have adequate education or knowledge about specific health topics and were not sure how to find this information. Most YP said they did not know how to look after themselves or their health correctly and did not know how to access relevant health services.

*I know some of these things might seem stupid to people that have had parents and stuff and people in their life. But a lot of these young people, they don't have that much education around some things because of the neglect that they've received from their parents. [YP02]*

It was evident that YP were often unaware of the routines and life skills needed for good health and had a poor understanding of normal developmental changes in their own bodies. Two young people described what this looked like in practice:

*I was putting a whole handful of shampoo in my hand. And running it through fairly short hair. I didn't know how to brush my teeth properly. I basically just put some toothpaste on. Brushed back and forth a bunch. And then spat out. I was cleaning the front of my teeth, just the bases of them. A lot of that stuff was just me winging it. [YP07]*

*I didn't get a lot of information about what was important for health as a female ... like pap smears and all that kind of thing, I know nothing about that stuff. But also general hygiene things around being a female. That was stuff that I had to learn on my own. [YP01]*

Many participants acknowledged that they had to seek out education from other sources, such as school or through their peers or media. School was mentioned by a number of young people as a source of knowledge, indicating that it is a critical enabler for health information, 'I knew from school that doing exercise was healthy, but it wasn't a conversation that was had in care itself about it.' [YP02] Common topics of health that participants reported having little to no knowledge about while in care included sex education, healthy eating and cooking skills, menstruation (for females), dental care, and mental health.

*... they don't really teach it. You do a bit of shopping ... But no one teaches you anything. There is zero, nothing like contraception. Nothing like that. Oh, here is medicine, we'll give you the safe amount. [YP03]*

Other young people simply watched others around them, 'The stuff that I did learn in the system, it was a really slow process of just observing other people and hoping that I could use that myself.' [YP01]; or relied on friends and entertainment sources, 'I think it was exposure from friends and from people



*I was living with. And during living on my own, access to the internet. I got heavily into watching House MD and a few other medical dramas and that. And then just through entertainment, pop culture, video games.'* [YP07]

For a number of these young people, it was once they had exited from care that they learnt about health and what to do to support good health:

*I learnt that through my partner's father. He's very much into looking after your health with food and exercise and things. So, he helped me out there, and then I just basically did my own research because DHHS didn't do anything.* [YP06]

*I got most of my information from my housemates.* [YP09]

This lack of health education and promotion has lifelong implications because the skills needed to promote healthy habits are not embedded into the lives of these young people. There were mixed experiences about the knowledge and life skills needed to obtain healthcare in Australia. For Australians, this revolves around getting a Medicare card that enables access to the public health system. Obtaining this card can be challenging, when identification documents, the potential lack of fixed address and other care related factors impair this process. For some, this took a long time: *'Just getting taught how to do the basic stuff around going to the doctors and having a Medicare card and all that kind of stuff. A lot of that didn't happen until after I was 18.'* [YP01]; or never happened at all: *'I still don't know what I'm meant to do when it comes to renewing Medicare. I don't really understand how Medicare works in public hospitals, with surgeries and all that sort of stuff.'* [YP09]. For one young person, their carer played a vital role in setting this up, demonstrating that it is possible for carers to fulfil this role in YP's lives:

*The supervisor I had at the family group home, she organised it all, well, with me. So, she took me to the bank when I was probably about 15, which is usually the role of the case manager, she took me to Medicare and she taught me everything really.* [YP10]

### **Reactive versus active**

YP described a lack of preventative approaches when it comes to health, and instead described the care received from workers/carers as being reactive and crisis driven:

*The one time I got a response around my mental health (before I had access to a psychologist), was putting a knife to my wrist in front of carers ... For me, that it had to get to that point in order to get a reaction or to get someone to take me to actually see someone, was pretty extreme.* [YP01]

They felt that carers were often 'putting out fires' rather than helping the YP to thrive and grow. This kind of care was often provided to YP in response to immediate physical health problems. Some YP also described feeling uncared for because their health concerns were not at a crisis threshold. Indeed, they described feeling left 'under the radar' or unnoticed, while other YP in their placement received more immediate or focused health care because they exhibited more observable health concerns (i.e., broken arm), which drew more attention to their problems.

*This wasn't the first time [health need was neglected]. A lot of the stuff is focused on the young people who are outwardly expressing their need. Seeing the people that are really in crisis, that impacts a lot, but I was just quiet when I was a kid in my self-expression, and I think it's like that for a lot of young people.* [YP03]

### **Low expectations**

Many participants reported that their carers, workers, services, and the OoHC system itself, had low expectations of the YP and viewed them negatively. They explained how carers often expected YP to disengage from help or health services and did not expect the YP to improve their health status or thrive after care. Because of these expectations, YP felt that carers would not often attempt to foster or encourage good health. This also filtered down into the YP's own views of their health and the care system. As a result,



many participants described a desensitization towards trauma or negative experiences and had low expectations or 'lost hope' about possible improvements in their health outcomes.

*... it's the attitude that, oh, they're just a resi kid ... If we give them a service, they're not going to follow through. Or if we get them this appointment, oh, they're just going to drop out or they're not going to go. [YP09]*

### **Our voices matter**

YP consistently emphasized their desire to be listened to about their health and to be involved in health-related decisions that affect them directly. Within this third major theme, four sub-themes were identified: (a) Young people feel powerless; (b) Relationships are key to young people opening up and feeling cared for; (c) Agency versus sole responsibility; and (d) Concerns need to be taken seriously.

#### **Young people feel powerless**

YP spoke about experiences with their workers/carers where they felt they had no power or autonomy to make decisions and/or be part of discussions around their health needs and health care. Often regular doctor or dental check-ups were not made in consultation with the young person: *'They more or less just came up to me, you're due for a check-up, and we're going to book you in on this day' [YP09]* or *'dentists were every six months ... I was told in that week when I had an appointment.'* [YP07]

It was clear that YP frequently felt unheard when raising their concerns around their health and other aspects of their lives. Some participants said this was due to their age, where the adults around them, particularly carers, did not feel the young person was old enough to understand their needs. Other participants said this exclusion was due to their carers feeling that the adults always knew what was in the best interest of the young person. The YP often recalled times where this assumption was not the case and decisions made on their behalf were more damaging to the problem. YP reflected on experiences where their health concerns would have been better addressed if they had the chance to speak up and be listened to. Nonetheless, YP generally felt listened to by doctors and other health professionals.

*They don't believe that young people know what they want and they often make assumptive decisions based on what they view as the best interest of the child ... they manipulate you to make it appear that you have a choice, but you never did. [YP09]*

#### **Relationships are key to young people opening up and feeling cared for**

YP noted the importance of having relationships and connections to carers to foster good health outcomes; without a relationship with the young person, education and conversations about health were not conducted, or if they were, it was at a superficial level. YP reflected on experiences of successful relationships with carers, or the lack of connection with carers, and how this affected their health. YP described how the possibility of a strong connection would have allowed them to feel cared for, safe, and comfortable to open up and share their health concerns without the fear of being judged, dismissed, or ignored. The need for trusting and respectful relationships was emphasized frequently by the participants. However, many YP felt they did not have these relationships and felt they missed out on the positive outcomes of having strong connections.

*I was struggling for so long with depression and anxiety and it was so hard to convey to them how you felt. And they didn't give enough effort into showing empathy or care whenever we had our meetings. I never really connected with anyone. It never felt like I had a good relationship with anyone. It honestly just felt like they thought I was crazy. [YP06]*

#### **Agency versus sole responsibility**

YP often spoke about needing to have a healthy balance between giving YP agency and a voice, but also recognizing that some YP may not be able to identify their own health needs. They spoke about the importance of feeling heard but also not feeling that they have the sole responsibility to raise concerns. YP agreed that it was important for their carers to also be able to pick up on

signs or 'red flags' of ill health within a young person. Some participants noted times where they were asked if they were experiencing any health issues and the young person felt unable to answer the question because they found it difficult to identify if there were any health problems. This was particularly true for described experiences of poor mental health or mental health concerns.

*150% we need to be included because our voices matter, massively. Because it's our bodies, it's our self, it's our minds, it's our hearts. We need to be part of it and not just be controlled like some puppet. [YP05]*

*It's complex. Looking back, I didn't know what I needed when I was younger. I think they [YP] should be included, but I also think they need responsible people around them to help make those decisions. [YP09]*

### **Concerns need to be taken seriously**

Every participant from all types of care described at least one time where their health concerns, when raised, were not taken seriously or were dismissed by their carers or workers: *'I feel like I was seen more as a problem than as someone that needed help. And all I wanted was someone to actually listen to me at the time, but no one was listening.'* [YP01] This dismissal of concerns occurred through a range of ways. Some YP were told they were being manipulative or attention-seeking (i.e., wanting time off school), others were told the concern was not a true concern or *'was not that bad'*. For example, one young person recalled how their carer informed them that a stomach ache was not a physical health concern, but rather *'just in their head'*. YP described these dismissals of their health issues as damaging or unhelpful to their long-term health (e.g., persistent mental health concerns) as the concerns were rarely addressed while in care and have since worsened. In some cases, this lack of belief extended to being treated by health professionals in hospital, perhaps demonstrating a bias towards children in care: *'I once went into hospital because I had appendicitis. They had me in the hospital for a week beforehand because they didn't believe that I actually had pain. They sort of just treated me like crap. They actually then removed the appendix and discovered it was appendicitis.'* [YP09]

### **Carers need support to better meet young peoples' health needs**

YP were in agreement that carers would benefit from additional education, knowledge, skills, and greater consistency in their role to more effectively meet the health needs of YP in care. Within this final major theme, two sub-themes were identified: (a) Lack of professional development; and (b) Need to address the high staff turnover/inconsistency.

#### **Lack of professional development**

Participants believed that workers and carers lacked professional development, including the knowledge and skills needed to address YP's health needs and/or concerns. As above, poor physical health which may be a consequence from a cold or injury were spoken of as easily identifiable and healthcare could be obtained for this. However, there were cases described where the symptoms that the young people described were normalized and reflected a lack of knowledge about certain health conditions:

*It would have been good to know the signs of having an illness like endometriosis. I told my mum and I told my foster mum. Obviously, they didn't really know much about that sort of thing. They're just making me feel like that all that stuff's normal, when it wasn't. [YP02].* On the other side of this spectrum, a young person with a diagnosed genetic condition tried to educate their carers about their symptomology to strengthen their capacity to provide care: *"We printed our own information on the things that I have and we'd say, 'please read this' to get an idea of what it is that I have so at least you know. And I don't think they ever just really even made the effort to understand"* [YP06]

Poor mental health, which is not something tangible or easily quantified, was often not identified – by young people or carers alike:

*I think it's hard for a lot of young people to recognise, especially if they've lived their entire life in abuse, that they might not be okay. I didn't know to begin with that I was suffering from mental health, just because I'd known trauma my entire life. [YP01]*

Numerous YP reported that they were often misdiagnosed:

*My anxiety was pretty bad, so I actually did get stomach pains, and then the doctor just said, oh you need some Nexium [medication] because you've got a build of hydrochloric acid in your stomach or something, causing me to be sick. And I'm like, okay, when really I was just getting bullied at school. [YP02]*

Others had issues go undiagnosed throughout their care experience by carers or were not appropriately supported to access relevant health services – especially mental health services:

*They saw physical health, oh physically fine, and social health going to school and all that sort of thing, so therefore I was fine. But really I wasn't. [YP04]*

Participants recommended that carers would greatly benefit from more health-related professional development, including being able to recognize the signs of poor mental health.

*Everyone can't be healthcare professionals but it's about sometimes using your common sense and going, their teeth look really yellow, maybe they're not brushing their teeth properly. Also being more observant with the young person about their behaviours ... Sometimes young people, if their appearance isn't looking too great, they could be struggling with a lot of depression and stuff like that. It's about noticing those things that the young person isn't telling you as well. [YP02]*

### ***Need to address the high staff turnover/inconsistency***

The YP with previous experience in residential care described their frustrations towards the high staff turnover or inconsistency of staff throughout their care experience and reported that this negatively impacted the workers' ability to meet their health needs. In particular, YP described how this was often detrimental to health communication and YP said they were unable to get their health needs met often due to the transience of staff, i.e., staff in residential care changing daily because of the shift work nature of their role. The long process of workers learning about each young person and their specific health needs meant that by the time workers were able to understand the young person and their health needs, they had moved out of the young person's life. Similarly, some YP with a foster care experience reported that multiple placement changes also disrupted their consistency of care. YP reported feeling let down, especially if they were required to change placements after a carer had taken the time to really understand their health needs. This meant that they had to start the process all over again with someone new.

*I think part of the reason around that [difficulty meeting health needs] is you have workers coming through the house on rotatory shifts. And new people coming in and old people leaving that often, that they don't get to know you that well. [YP07]*

Another young person spoke about the lack of safety and space to be vulnerable about their health when the staff change frequently, 'It's uncomfortable when there's constant changeovers and all that stuff when it comes to it, because health is a very personal thing. It's something that's not easily talked about as well.' [YP02]

## **Discussion**

The aim of this study was to explore the experiences and perceptions of YP living in OoHC in relation to their health. By engaging YP at various stages of the research process through co-design and qualitative methodologies, this study gained insight into YP's perceived health needs, participation in health care planning, and barriers to improved health. Key findings uncovered in this study indicate that: (1) the health needs of YP in OoHC are often not addressed adequately; (2) the OoHC system presents numerous barriers to nurturing and improving YP's health outcomes; (3) YP recognize the importance of, yet lack, opportunities to participate in decisions that affect their health; and (4) carers require significant additional support, education, and training to better recognize and address YP's health needs.

Not surprisingly, mental health seemed to be the main health concern that YP reported experiencing when reflecting on their time in care. This is not dissimilar to recent research by Conn et al. (2015) and Ford et al. (2018). When participants spoke about their mental health, they often felt that it was rarely addressed appropriately, with some YP describing it as being completely neglected and/or going unnoticed altogether. YP believed that carers either missed the signs or were unable to recognize the signs of poor mental health. In cases where participants did speak about their carers recognizing their mental health concerns, they still described inadequate intervention in response to the identification of those needs. These findings suggest there is a need for training and education to upskill key stakeholders in the OoHC sector to recognize these concerns and act accordingly (i.e., linking YP with a psychologist).

The current findings suggest that YP were often not involved adequately in their care planning and/or they could not recall their care and placement plans, including health related outcomes. Participants in the current study described leaving care not knowing how to manage their own health needs independently nor how to access appropriate and relevant health services. Active and ongoing participation in everyday health-related decisions is necessary for YP in OoHC to increase self-efficacy and develop skills that prepare them for adult decision making and independent living from the age of 18 (Ford et al., 2018; Taylor & Marshall, 2018). Therefore, it is clear that greater emphasis must be placed on the importance of completing care and placement plans, ensuring that health outcomes are included, and that YP have the opportunity to actively participate in decisions made regarding their health. YP also need additional education, support, and opportunities to navigate the unique and persistent health needs that they identified. Teaching YP the necessary skills, knowledge, and strategies to help them improve their health outcomes while they are still in care is crucial for the OoHC system to begin to foster better health outcomes. This is especially important given research suggests that health concerns identified during adolescence can become ongoing issues that persist into adulthood, after YP exit the OoHC system (Anda et al., 2006; Norman et al., 2012).

There is a growing body of evidence which calls for YP to be included in decisions that affect them, including decisions relating to their own health and wellbeing (Ford et al., 2018; Lansdown, 2011). In contrast to this advice, the current findings indicate that YP generally did not feel listened to or heard and were not always able to contribute to decisions around their health or healthcare plans. This is similar to previous research, which found the unique perspectives, experiences, and opinions of YP are often not considered, nor are they provided with opportunities to be listened to, particularly in relation to their health (Finan et al., 2018; Ward et al., 2002).

In addition to not feeling heard, the YP in our study also discussed some key system barriers to noticing, addressing or improving health outcomes among YP in OoHC. In particular, when talking about how their health needs were addressed, YP spoke about carers and workers appearing to adopt an immediate and crisis-driven approach to care. That is, YP felt that underlying health issues (i.e., ongoing depressive symptoms) took a back seat to observable health emergencies (i.e., broken leg that warrants a hospital visit). This often resulted in less observable symptoms going unnoticed and unaddressed. This may help explain previous findings which indicate that carers consistently underreport the presence of health concerns among the YP in their care, as well as discrepancies between reported and diagnosed health issues (Bulat, 2010; Gopakumar et al., 2018; Kaltner & Rissel, 2011). Participants also talked about feeling like carers were simply fulfilling system requirements and viewing health care as 'ticking boxes' on a checklist, rather than providing genuine concern for the young person's health. This extended to following-up and/or offering ongoing support for a young person experiencing specific concerns. Previous research has reported carers often do not notice, are unaware, and/or cannot identify YP's health needs (Grace et al., 2018), and these statements are consistent with the current findings. Subsequently, it is clear that carers need additional training and education to be able to understand, identify, recognize and respond empathically to YP's health concerns, whilst also managing the competing priorities of the OoHC context (i.e., crises and system requirements, such as paperwork).

It was encouraging that some YP in the current study were able to provide examples of positive experiences of their health needs being met while in care. A consistent factor among these positive

experiences was that these YP had a positive and meaningful relationship with an adult who advocated on their behalf. In contrast, inadequate health care was linked strongly to the absence of a meaningful relationship and/or connection between the young person and their caregiver(s). This finding is not surprising given research has found that healthy relationships between YP and adult role models are linked to better psychosocial, developmental, mental, and physical health outcomes among YP in OoHC (Mauder & Hunter, 2008; Sen & Broadhurst, 2011). However, this is often hampered by a system which lacks consistent adult role models (due to regular staff turnover), multiple placement changes and 'system requirements' (i.e., keeping case notes) that prevent the development of meaningful relationships (Everson-Hock et al., 2012; Kaltner & Rissel, 2011; Murray et al., 2011). Consequently, one avenue for the provision of improved health care, is a focus on building a system that fosters stable and consistent relationships between YP and their caregivers. This is supported by the findings of the recent Inquiry, which also emphasized the necessity of consistent contact between workers and YP to build trust, respect, and genuine relationships, and subsequently greater opportunities for YP to be involved in decision making (Commission for Children and Young People [CCYP], 2019). Above all, ensuring the development of meaningful relationships between YP and their carers/workers in OoHC needs to be made a priority in this context as it is seen as foundational to improving health outcomes.

A significant and necessary strength of this study was the adoption of a co-design approach at all stages of the research process. Our study went beyond previous research in this area and consulted YP with a lived experience in OoHC on the overall study design and methodology. This novel approach allowed YP to provide feedback on the relevance and appropriateness of the overall study design, the structure and design of participant materials (i.e., recruitment flyers) and the semi-structured interview schedule. This empowered YP to give voice to the issues that are important to them, as well as their opinions and preferences on how research with YP should be conducted. This led to major revisions to the research project that would have otherwise been neglected if a co-design approach was not used.

Furthermore, this study acknowledges that YP are experts in their own lives and should be recognized as agents who are capable of contributing to decisions that affect them (Grace et al., 2018). The adoption of a qualitative design enabled an in-depth exploration of YP's health-related experiences, concerns, questions, and preferences. We argue that co-design methods should be embedded and included in future research to ensure YP are included in research in a way that is meaningful and acknowledges their right to participate. The information collected in this study may lead to more creative and relevant solutions, including innovative approaches to inform policy development, and tailored services that truly meet YP's needs (Monson et al., 2019).

The current findings should be considered in light of some methodological limitations. Firstly, purposeful sampling may have posed challenges to the generalizability of these findings as the participants in this study only represent a small percentage of the target population. For example, this study did not include any participants who reported being homeless, despite reports that at least 33% of YP leaving OoHC become homeless in the first year (CREATE Foundation, 2013). Another possible limitation of this study is the fact that YP who were currently in care were excluded due to ethical difficulties in gaining consent from parents and/or guardians. Interviewing YP who are currently in OoHC may have provided new insights about the current OoHC care system and services. Including a sample of YP presently living in OoHC could also limit the possibility of retrospective recall bias. As participants in the current study were asked to reflect on experiences that occurred multiple years ago, it is possible that the accuracy and completeness of their perceptions may have weakened over time (Blome & Augustin, 2015).

In summary, the findings of this study suggest that when a young person was succeeding or 'doing well', this appeared to be in spite, rather than because, of their care experience. Given the vast resources, funding, and access to health services available to YP in OoHC (Department of Health and Human Services [DHHS], 2019), the system has a great opportunity while YP are in care to address their health needs and improve both their short- and long-term health outcomes. Moving forward, it is important that the limitations of the current OoHC system are recognized and the following four major recommendations are considered in relation to system reforms to improve the health and wellbeing of YP living in OoHC.

The first recommendation is the development of training and/or professional development to upskill carers in identifying, responding and managing a young person's health needs. This needs to extend beyond simply following mandated guidelines for accessing primary health care and should include a strong focus on the development of strong connections and meaningful relationships between the carers/workers and the YP in their care. Secondly, creating a home environment where carers are attuned to the needs of the YP will help ensure that important health needs will not go unnoticed nor minimized, and that YP are better able to self-manage their own health concerns (Pizzirani et al., 2019). Supporting carers to develop and maintain respectful, meaningful, and consistent relationships with YP is key to improved health outcomes, as shown by the study's findings and related literature (McWey et al., 2010; Pizzirani et al., 2019; Sen & Broadhurst, 2011). The third recommendation is that greater emphasis needs to be placed on educating carers (and YP) about preventative health practices and approaches. Adopting an early prevention model that educates both the carers/workers and YP about varying health issues would not only ensure that the health concerns of YP are identified and addressed but would also empower YP by increasing their capacity to better manage their own health independently. This could include giving them the necessary skills, knowledge, and strategies to help them improve their outcomes while in care and beyond, as well as teaching them how to access appropriate health services once they live independently. The final recommendation is that all future work concerning this population, including research, and the development of any training, policies, programmes and services, must include YP in the development process to ensure that their voices are being listened to, acknowledged, and informing change. In addition, future research should adopt a co-design approach that ensures the voices of YP are heard and acted on throughout the whole research process. This will honour the YP's right to participate, empower them, and respect them as experts in their own lives.

## Notes

1. Internationally, this population may be referred to as 'looked-after children, children in 'public care', 'children in care', and/or 'care-experienced'.
2. Care and placement plans outline the day-to-day activities for caring for a child or young person, including their short- and long-term needs and how these needs will be met.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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