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Health issues of older people with intellectual disability in group homes†

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Abstract

Background—This paper explores how group home staff in Victoria, Australia, responded to residents with an intellectual disability (ID) as they developed age-related health conditions.

Method—The analysis was based on a longitudinal study that followed 17 ageing group home residents over a 3-year period. Eighty-three interviews were conducted with 30 group home staff in 17 group homes. Dimensional analysis, a variant of grounded theory, guided data collection and analysis.

Results—Findings revealed that the organisations all had systems in place to address health issues. However, the results also suggest an inability of staff to differentiate between significant health conditions and normal age-related changes, thus contributing to delays in care for serious medical conditions.

Conclusions—Lack of knowledge about normal ageing and an absence of organisational policies influence timeliness of diagnosis and treatment for people with ID. Group home staff could be more effective advocates for older residents, leading to improvements in health outcomes, if they had basic knowledge about normal ageing and symptoms of common age-related illnesses and if group home agencies provided clearer guidance to their staff. The study has implications for staff education and organisational policy development for group homes.

Keywords

intellectual disability; ageing; group home; health

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Introduction

Longevity has increased dramatically for people with intellectual disability (ID) over the past 20–25 years. People with mild ID can now expect to live as long as their peers without ID (Fisher & Kettl, 2005; Ouellette-Kuntz et al., 2005). The likelihood of illness increases with age for all people, but those reaching old age with ID can expect a greater burden of illness than people without ID (Bowers, Bigby, & Webber, 2009; Janicki, Dalton, McCallion, Baxley, & Zendell, 2005; Janicki et al., 2002; Thompson, Ryrice, & Wright, 2004).

The increased illness burden for people with ID has been well documented and attributed to multiple sources. Some people with ID have genetically acquired health conditions. For example, people with Down syndrome are at increased risk for heart conditions and dementia (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2000). Older people with ID also experience a disproportionate burden of health conditions based on lifestyle (Haveman et al., 2010). The greater incidence of obesity in people with ID increases their risk for diabetes, heart disease, and osteoarthritis (Melville, Cooper, McGrother, Thorp, & Collacott, 2005; Ouellette-Kuntz et al., 2005; Prasher & Janicki, 2002).

Other factors such as prior institutionalisation, a lifetime of poor access to healthcare services, dismissive attitudes of healthcare providers resulting in less reliable follow-up, diagnostic overshadowing (focusing on the disability), low rates of screening, and communication challenges make diagnosis and appropriate treatment less likely and have all been linked to poor health outcomes in later life for people with ID (Brown & Gill, 2002; Connolly 2002; Emerson, 2002; Fisher & Kettl, 2005; Ouellette-Kuntz et al., 2005; Robinson, Dauenhauer, Bishop, & Baxter, 2012; Webber, Bowers, & Bigby, 2010). People with an ID are also at high risk of misdiagnosis (Webber, Bowers, & McKenzie-Green, 2010). Confusion and behaviour changes, which often reflect underlying illness or untreated pain, are frequently misdiagnosed as dementia (Gibbs, Brown, & Muir, 2008; Tuffrey-Wijne, McEnhill, Curfs, & Hollins, 2007).

Many older people with ID are relocated to group homes when parents die or are no longer able to provide care. Adding to the many people with ID who were moved from institutional settings to group homes in the 1970s–1990s (Manning, 2008), there is now a substantial number of people in group homes nearing old age (Bigby, Webber, Bowers, & McKenzie-Green, 2008). The impact of increased longevity of people with an ID (Evenhuis et al., 2000; McCarron & Lawlor, 2003; Prasher & Janicki, 2002) is a pressing issue for group home providers, who are contending with changed health and social care needs of residents who are living longer and developing age-related health conditions. Although group home staff in many countries are rarely trained to care for people with health conditions, group home residents rely on them to know when medical attention is needed (Bowers, Webber, & Bigby, 2012; Iacono, 2010). This paper explores how group home staff interpret and respond to symptoms of illness in older group home residents.

Methodology

The study was conducted over 3 years, and included interviews with group home staff and family members associated with older group home residents. For each of the 10 residents who were relocated to residential aged care during the course of the study, a staff member in the facility was also interviewed. Group home staff were contacted at the beginning of the study, and then at 6-month intervals throughout the 3 years. This paper reports only on interviews with group home staff and the period prior to a resident relocating to aged care.

The study was conducted by an interdisciplinary team using dimensional analysis (Bowers & Schatzman, 2009; Kools, McCarthy, Durham, & Robrecht, 1996; Robrecht, 1995). Dimensional analysis is a second-generation grounded theory methodology based on symbolic interaction (Blumer, 1969). As such, the methodology is specifically designed to elicit the social constructions of participants, and to illuminate how participants understand and experience the phenomenon of interest. The methodology is particularly well suited for research that seeks to learn how participants understand a situation and how their understandings relate to the actions they take. The purpose of the methodology is to generate conceptual renderings from data.

Setting

The study took place in Victoria, Australia, in 17 group homes, each with four to six residents, and at least one resident over 45 years. The mission of the group home system in Australia is to support residents to develop skills, make choices about their lives, and be active in their communities. Rostered staff support household management and resident self-care, personal hygiene, and community participation (Department of Health, 2011). Most homes have sleepover staff who are available for emergencies but not generally expected to be awake during the night. Health-related training is limited to basic first-aid training (Iacono, 2010).

Participants

The 30 group home staff were all in supervisory positions but were also actively participating in daily life of the group home. All group home staff interviewed had formal training in disability. None of the group home staff in this study had received formal training to care for older people or for people with serious or chronic health conditions. Each of the participating group home staff had at least one person over 45 years with an ID living in their home during the study.

Interviews

Following the initial interviews, group home staff were recontacted at approximately 6-monthly intervals. In situations where residents were experiencing age-related health changes, staff were reinterviewed. The number of interviews per staff ranged from two to six (total 83 interviews from 30 staff). Only one staff member declined to be interviewed. Initial interviews were conducted in person at the agency. Follow-up interviews were conducted via telephone.

Data collection

Data were collected through in-person and telephone interviews. Follow-up phone calls allowed the research team to observe responses to resident health conditions as they occurred, minimising the need to rely on retrospective accounts. Interview questions evolved in response to ongoing analysis. Initial interview questions were very unstructured, simply asking staff to talk about the ageing of their residents and the implications for group homes. Later questions were increasingly focused, allowing the research team to explore emerging categories in some depth. As it became apparent that behaviour changes were often the first symptom of an illness, staff were asked to describe how they had responded to behaviour changes and how the situation evolved over time. Group home staff were invited to participate based on the presence of at least one older adult in one of their group homes. Each of these residents had consented to participate in the study. Group home staff described ongoing ageing and/or health concerns of the residents participating in the study. They also frequently described how they had, in the past, responded to other residents with similar symptoms or concerns. None of the past residents were identified. Thus interviews included specific descriptions of staff experiences with current residents and more general experiences with past residents.

Analysis

An interdisciplinary research team of three researchers representing nursing, sociology, and social work, conducted the analysis, using open, axial, and selective coding (Strauss, 1987). Interviews were recorded, transcribed, and analysed immediately following the interviews. Initial interviews with group home staff included multiple descriptions of former group home residents whose medical conditions had been discovered very late in their illness. During early interviews there were numerous references to the “inevitable” age-related changes in residents, many which could also have been symptoms of serious illness. In the follow-up interviews staff members were asked whether any residents were having difficulties related to ageing or illness, and how they were responding to them. Dimensional matrixes of emerging categories and relationships among categories were reviewed by team members and confirmatory searches of data were conducted. Member checking was conducted with participants to confirm, adapt, and expand evolving themes. Consistent with symbolic interaction and the grounded theory method, categories were generated based on how the group home staff members organised and explained their responses to changes in residents. Included on the research team was a geriatric nurse practitioner who was able to identify changes that might also have been symptoms of illnesses. (In two instances, the research team intervened to suggest that a resident be seen by a healthcare provider.)

Ethics

This research was approved by the human research ethics committees at the three universities where the authors are employed. Pseudonyms have been used where names of agencies or people appear in the quotations, and any identifying material has been removed. Each person interviewed in the study was given a separate ID number (prefixed by a hash [#]), which is used to identify the source of each quote presented in the findings.

Results

Two broad issues related to the health care of residents were identified. The first part of the findings delineates the issues staff encountered and the steps they took to maintain the health of residents in a group home. The second part outlines and contextualises accounts and identifies possible sources of delay in seeking diagnosis and treatment for possibly serious health conditions.

Maintaining health of people ageing with an intellectual disability

Although not mandated, staff in each organisation reported that all current and past group home residents received annual health checks from their primary care provider/general practitioner (GP). Staff reported that annual health checks had led to the identification and treatment of many conditions such as diabetes, high blood pressure, and elevated blood cholesterol.

Older adults in Australia routinely receive reminders from a government agency for routine screening tests such as mammograms and faecal occult blood tests. GPs routinely remind women when it is time for their next pap smear. Responses to these screening reminders varied considerably across agencies, across homes within the same agency, and even among staff in the same group home. Although some staff explained that women with ID would not tolerate a mammogram or pap smear, other staff, sometimes in the same home, acknowledged the challenges of mammograms but described finding ways to assist women going through the test.

In some cases, GPs influenced staff attitudes toward residents having pap smears, mammograms, and prostate examinations. Some staff described how a GP had told them that women with ID did not need pap smears or would not tolerate a pelvic exam:

We get a lot of feedback from doctors, especially about female's pap smears. Well they're not sexually active so they don't need a pap smear. #63

One staff member reported a GP's concern about being accused of assault if he conducted an internal examination on a woman with ID:

I find it really difficult to get Dr Smith to give the same standard of testing as we have ourselves. I appreciate the intellectual disability, doctors can't just do a pap smear or a prostate test because it could make a case for assault ... And that's not just one doctor, I've found the view throughout ... you have to decide, do I look around for a doctor who will do it or do you take the medical advice. #9

Staff also described physical and emotional challenges to routine screening, citing these conditions as reasons that tests were not done:

Mammograms, you know we find that some of those tests then become difficult because of physical abilities, the fact that someone's in a wheelchair and you can't get them out of the wheelchair in the doctor's rooms. #63

Some staff described advocating routine testing, despite reluctance of GPs. Others did not:

We had a gentleman with Down syndrome and he was terrified of doctors and we couldn't get an injection and we couldn't do a blood test. We couldn't do anything. So what we did instead of taking him to the doctor we brought the doctor here. #14

Some staff expressed discomfort or disgust with the procedures required to obtain a stool sample for a faecal occult blood test and decided not to follow through. Significantly, none of these staff members was able to describe the purpose of faecal occult blood tests or the increased risk for residents who had spent time in institutional settings. There were some staff who appreciated the importance of acting on all screening recommendations and made sure there was follow-through on all screening reminders.

Contrary to what has been reported in other studies (Beange, McElduff, & Baker, 1995; Kerr, Richards, & Glover, 1996; Lennox, Diggins, & Ugoni, 1997; Lindsay, 2006), many group home staff interviewed for this study described how effectively GPs supported group home residents:

Oh, they have their own doctor who they've been going to see for, oh, five years, four years, something like that. And she's an excellent, excellent with them. No, we usually access what everyone else accesses, we don't have a problem. #37

Staff described planning strategies with GPs such as increasing appointment times, ensuring consistency/familiarity of providers, taking care not to mention things that residents found frightening, setting up appointments so group home residents would not have long waits, taking extra time to put the person at ease, and sometimes making house calls:

There was a doctor who was fabulous and would actually come and do home visits. #4

Although many GPs were described quite positively, some were seen as neither responsive nor sensitive to the needs of people with ID. When GPs were perceived as unresponsive to the needs of people with ID, staff often changed to someone who was known to be more responsive:

... she's got Barrett's disease. ... And they took her to the local GP, to get a referral for the follow-up, and he said: "Well, yes it doesn't really matter that the follow-up hasn't happened, because, after all, she's not normal." ... And then they changed doctors, after that. #94F

As most group home staff had no formal training in health issues, they described relying on GPs and other providers to determine when follow-up was needed. Acting on the assumption that if something had been amiss the doctor would have rung them, commonly, staff did not feel a sense of urgency to follow-up on tests that had been ordered:

There's a little growth on his tummy which we've had biopsied. ... And I haven't had time to ring them [the doctors]. #8

One staff member expressed some confusion over whose responsibility it was to make sure things were done:

Yeah but ultimately, whose responsibility is all that. Do I have to push it? Should someone else? #9

However, a few group homes had established formal systems for ensuring appropriate follow-up for new and ongoing health concerns. As the manager of one group home organisation stated:

The staff have been told to always bring a good record back ... what was done and make sure I know about any medications that were added. So I have a list of everyone who had an appointment ... tests they had. If we don't get results, I get on the tellie [phone] and call. ... find out where they are, why we don't have it ... what we need to do. #96

In organisations with clear policies or practices for follow-up, medical tests, and screening, staff described being aware of procedures or participating in follow-up to ensure tests were completed. In some group homes there were policies or routine practices in respect to only a few tests and screening procedures. In the group homes without such policies, follow-up was often left to individual staff or family members. Sometimes this follow-up was overlooked. Although none of the organisations had policies regarding pap smears, mammograms, or faecal occult blood tests, a few had formal policies for dental appointments, and hearing and vision exams. Staff in these homes indicated an awareness of the requirements and confirmed that all residents had their hearing tested. In the absence of clear organisational policies, staff (and sometimes family) were left to decide what should be done.

In addition to health screening tests, staff were faced day to day with changes in residents' health conditions. Many group home staff provided accounts of residents who had symptoms for significant periods of time before they were taken to their GPs, as staff had believed the symptoms simply reflected normal ageing. Many of these accounts related to past residents, although some were still living in the group home.

Delays in seeking care

It's just ageing—When asked about older adults in their group homes, staff spontaneously described many changes they had observed in past and present residents that they generally attributed to getting older. These included a general slowing down, changes in continence, mobility, toileting, sleep patterns, and cognition, and unusual or challenging behaviours. Although each of these can be signs of significant illness, many group home staff interpreted these conditions as normal and expected for older adults. In fact, only one staff member questioned whether generally slowing down was “just getting older.”

Other common symptoms described by group home staff as related to getting older were disrupted sleep (nocturnal wandering and excessive fatigue), decreasing mobility, and falling:

Yeah, he's wanted to sleep a lot longer. I think it's just age and you know walking it takes a lot of energy and I think it's just ageing more than anything else. #22

She's very well, she does have a problem sleeping sometime but I think this might be a bit of an age factor too, you know, you hear old people say: “Oh I can't sleep as well.” #13

Just being difficult—In some instances, a developing health problem was viewed by staff as voluntary behaviour and attributed to a resident just “being difficult.” One staff member explained urinary frequency and incontinence as a reflection of boredom:

He’s up at the toilet ... I believe that it’s a boredom thing, not so much boredom because he does a lot of things but coupled with the short-term memory he forgets.
#70

The link between these earlier symptoms and this resident’s later diagnosis of an enlarged prostate cannot be confirmed, but the failure to consider the possibility is significant, as frequent urination is a common early symptom of many serious illnesses:

... he had enlarged [prostate] ... his bladder wasn’t emptying properly, ... so he was flushing the toilet four or five times, then he’d go back to bed ... and then a minute later he would ... go again, because he hadn’t emptied his bladder. ... we got him onto a urologist to talk about having an operation. #70

Another resident was described by staff as becoming increasingly lazy over time. Although increasing fatigue can be a significant symptom of serious illness, this possibility was not considered. As one staff member said:

... you cant mollycoddle someone. If we’re sitting around for six months we’re not going to have the energy levels ... #48

It’s dementia—Challenging and unusual behaviour, as well as a range of physical symptoms, were commonly assumed by staff as indicating the onset of dementia. Staff reported that was common to interpret confusion, aggression, and uncooperative behaviour as indicative of dementia. For example, one staff member described how a past resident had been waking at night, was aggressive toward other residents, and refused to go to the toilet. Staff initially assumed the resident had dementia. However, after about six months he was taken to his GP who diagnosed the problem as a painful hernia that was disturbing his sleep.

Several staff confirmed that sleep problems were often assumed to be either dementia or just a sign of getting older. One group home staff member described a current resident who had been getting up frequently, waking other residents, and generally disrupting the house during the night. The resident was initially described by staff as “forgetting he had just gone to the toilet.” However, the staff member interviewed for the study accompanied the resident to the GP, as the problem increased, and was told that the resident had significant prostate disease that had caused an almost complete urinary obstruction.

In the previously mentioned examples, staff described how symptoms had often gone untreated until they were so disturbing that outside assistance was sought. Staff accounts revealed that delays in seeking medical help were particularly likely when symptom development or decline in functioning was slowly progressive rather than sudden in onset, and when symptoms were not disrupting the house or bothering other residents or when symptoms were intermittent.

Some staff accounts reflected the assumption that intermittent symptoms suggested a minor issue. When symptoms waned or disappeared, even when they recurred intermittently, staff

reported that they were often overlooked. Referring to a resident with serious heart disease, who was currently asymptomatic, one manager said: “The heart ... well that just got better” #48.

Adding to the likelihood of misinterpreting an illness symptom as dementia was the finding that staff commonly believed that dementia was inevitable in people with ID. In the context of high expectations for developing dementia, behaviour change in a resident was viewed as likely to be dementia. In short, it was the default interpretation for any behaviour change. In addition to confusion and clear changes in cognitive or language ability, staff frequently interpreted aggression, anger, and even moodiness as the beginning of dementia.

When behaviour was disruptive to the home, staff often described accepting such behaviour changes as sufficient evidence for dementia, sometimes moving quickly to a decision that the resident was no longer appropriate and must move to aged care:

We're pretty sure he has the early onset of dementia because all of a sudden he'll just sit and scream out in his bedroom or hit out at people, and he's never done that before, but it's just all of a sudden it'll come on and then it's done, and he'll get very upset about something and you wonder why, and that's just something he's never done before. #34

There were only a few interviews suggesting that staff had considered other possible sources such as medication side effects, underlying medical conditions or depression. Staff pursued many different strategies after deciding a resident was likely to be developing dementia. In some instances, residents were taken to their GPs. The GPs varied on the comprehensiveness of assessments before confirming or denying dementia. Some simply agreed with the diagnosis after hearing about the behaviour. Some ordered tests. Some referred the resident to a specialist.

A few group home staff described contacting family members to suggest they start looking for an aged-care facility, particularly when the behaviour was seen as disruptive to the home. Some staff, in an effort to protect the person from forcible relocation, avoided contact with healthcare professionals, as they feared the resident would be moved to aged care.

Staff acknowledged the difficulty in identifying health conditions, but generally perceived this as primarily related to the older person's inability to communicate clearly about their distress or to describe symptoms they were experiencing. A worker explained her non-action with regard to a resident who had exhibited significant behaviour change as based on the inability of the resident to communicate:

I don't know, Trevor wouldn't really tell you even if something was sore or stiff anyway. #3

Although most staff described themselves as adequately trained for their work (acknowledging that they had no formal training in either care of older adults or care of people with chronic illness), a few acknowledged that their training was not sufficient to care for people with health conditions:

We are not trained health providers. ... my background is in hairdressing. #65

One group home manager acknowledged the tendency of staff to overinterpret symptoms as dementia:

I'd love to have more training in dementia for them [staff] as well because people are very quick to put labels on other people, you know, you've really got to know a little bit more about what is dementia. #97

Other reasons for delay—In some cases, without any consultation, staff attributed new symptoms to a condition that had been diagnosed in the past. Many residents had longstanding swallowing difficulties related to their primary disability. For these residents, new or increased swallowing difficulties were often assumed to be “the same thing.” This was also sometimes the case when the condition had been previously diagnosed in another resident. Examples were found with choking, decreased mobility, skin conditions, and balance problems. When asked about delays in seeking a health consultation for a resident who had collapsed several times, the respondent said:

The staff were thinking he was having seizures because it was similar. ... [but then] I got a call at about 1.30 in the afternoon from a cardiologist at the Austin [hospital] ... talking about doing a pacemaker #29

Staff descriptions suggested that current symptoms were sometimes attributed to past diagnoses. When this happened, past strategies were used to address the current health problems. In one instance, a past diagnosis of pica was used to explain new episodes of choking. The choking was addressed by implementing strategies to prevent ingestion of foreign objects. Staff did not consider other possible explanations or approaches to choking, as they attributed the problem to pica.

Some delays in seeking health care resulted from a strong commitment to maintaining resident privacy and treating residents with respect. Staff described taking great care to avoid intruding on personal space, encouraging residents to dress and bath themselves and toilet independently. One consequence of this approach was that residents could develop serious health problems that were invisible to staff when the problem was covered by clothing. An older man, who was independent in personal care, was discovered to have advanced scrotal cancer. He was found to have a massively enlarged but not painful testicle when seeing his GP after fracturing his arm. The growth was discovered when he asked for help using a urinal in the GP's office. Another older man was found to have advanced melanoma on his abdomen when undressing during a visit to his parents'.

Discussion

The residents' inability to communicate about their symptoms, to describe them clearly to staff, in conjunction with staff assumptions that many changes simply reflected normal ageing, have the potential to cause long delays in diagnosing and treating. Communication challenges, diagnostic overshadowing, negative provider attitudes, and poor provider training (Robinson et al., 2012; Ward, Nichols, & Freedman, 2010) have all been, and continue to be, linked to significant levels of undetected illness and delays in seeking care for people with ID (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001, Haveman et

al., 2010; Robinson et al., 2012). This study demonstrates some of the processes by which these delays can occur, even in a formal care setting.

Although the need for better training for staff in care of people with ID has been identified (Ward et al., 2010), the study reported here highlights the importance of group home staff also having sufficient knowledge and support to identify symptoms that could indicate developing illness, seek appropriate medical attention, and advocate for residents when necessary. The symptoms most often identified by group home staff in this study are each potential indicators of serious underlying medical conditions. Lacking any formal training in ageing or age-related illnesses, and failing to recognise the significance of behaviour changes, symptoms were often interpreted by staff as “just ageing” or as reflecting the onset of dementia, with no exploration of other possible causes.

The misinterpretation of behaviour changes in people with ID has been previously identified (Robertson, Roberts, Emerson, Turner, & Greig, 2011), but this study provides further detail on how staff/caregivers attribute cause to commonly observed symptoms. This is significant as attributions of cause drive subsequent staff actions. That is, presumed cause determines whether medical consultation will be sought, accommodations will be made to lessen the impact of the problem, or residents will be recommended for relocation to residential aged care. When seen as ageing or dementia, staff often worked hard to support residents, putting off the day when they would have to move the resident to an aged care setting by avoiding contact with specialists who, they feared, might speed the relocation process.

Group home residents without sufficient verbal skills to directly describe their symptoms were only able to “tell” staff by communicating general distress, which was often seen as a behavioural problem. An important finding is that, although behavioural change has been well documented as the first symptom of many serious health problems (Evenhuis, 1997), behaviour changes were routinely perceived by staff as either just about getting older or the onset of dementia. This resulted in significant and continuing delays in diagnosis and treatment of illness. Failing to understand that symptoms of significant illness are often intermittent, staff often incorrectly interpreted the waxing and waning of symptoms as indicating that the problem had been resolved or was unimportant, also contributing to delays.

Organisational policies were found to be significant, accounting for clear differences in responses to screening and preventive care as well as follow-up for diagnostic work. The absence of clear organisational policies pertaining to symptoms and health conditions led to inconsistency in follow-up and potential delays in treatment.

Healthcare provider attitudes as a source of delay in identifying illness and treatment was only partially confirmed by this study (Robertson et al., 2011). Although there were descriptions of healthcare providers with negative and dismissive attitudes toward people with an ID, many primary care providers were described as sensitive to the needs of people with an ID and were willing to accommodate their needs.

Finally, the challenge of hidden signs of illness, such as the testicular enlargement previously described, raises important questions about how to ensure adequate health

assessment for residents while respecting their privacy, acknowledging that people with an ID may not be able to engage in the type of personal surveillance that people without an ID engage in on their own.

Limitations

A significant limitation of the study is the absence of medical records to confirm group home staff descriptions of medically related events and outcomes. It was not possible to confirm their accounts or to identify illnesses that might still be undetected. However, the group home staff accounts of how they understood and responded to the symptoms described suggests a gap in their knowledge that could easily lead to long delays in seeking care.

A second limitation is that the initial purpose of the study was to compare family, staff, and resident perspectives on age-related changes in residents. Thus, probing for greater depth in descriptions of symptom interpretation did not occur until after the first round of interviews.

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