

The psychosocial impact of undergoing prophylactic total gastrectomy (PTG) to manage the risk of Hereditary Diffuse Gastric Cancer (HDGC)

Running Head: *Impact of prophylactic total gastrectomy*

Nina Hallowell¹, Julia Lawton², Shirlene Badger^{3,4}, Sue Richardson⁵, Richard H Hardwick⁶, Carlos Caldas^{6,7}, Rebecca C. Fitzgerald^{6,8}

1. Ethox Centre, Nuffield Department of Population Health, University of Oxford, UK
2. Centre for Population Health Sciences, University of Edinburgh, UK
3. PHG Foundation, Cambridge, UK.
4. Institute of Public Health, University of Cambridge, UK
5. University of Cambridge, Cambridge, UK
6. Cambridge University Hospitals Trust, Addenbrookes Hospital, Cambridge, UK,
7. Cancer Research UK Cambridge Institute, University of Cambridge, UK
8. MRC Cancer Unit, University of Cambridge, UK

Correspondence to: Nina.Hallowell@ethox.ox.ac.uk

Ethox Centre, Nuffield Department of Population Health, University of Oxford, Old Road,
Oxford, OX3 7LF, UK

Telephone: 44 1865 617807

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Abstract

Individuals identified as at high risk of developing Hereditary Diffuse Gastric Cancer (HDGC) are advised to undergo prophylactic surgery - have their stomach removed - in their early twenties. Research with (older) cancer patients who undergo gastrectomy for curative reasons suggests that gastric resection has a number of physical and psychosocial *sequelae*. Because it is difficult to extrapolate the findings of studies of older cancer patients to younger healthy patients who are considering prophylactic total gastrectomy (PTG), the aim of this qualitative interview study was to determine the psychosocial implications of undergoing prophylactic surgery to manage genetic risk. Fourteen men and 13 women from the UK's Familial Gastric Cancer study who had undergone PTG were invited to participate in qualitative interviews. Most reported that undergoing surgery and convalescence was easier than anticipated. There was evidence that age affected experiences of PTG, with younger patients tending to report faster recovery times and more transient aftereffects. All saw the benefits of risk reduction as outweighing the costs of surgery. Surgery was described as having a range of physical impacts (disrupted appetite, weight loss, fatigue, GI symptoms) that had related psychological, social and economic implications. Those considering PTG need to be aware that its impact on quality of life is difficult to predict and negative *sequelae* may be ongoing for some individuals.

Key words: Hereditary diffuse gastric cancer (HDGC); prophylactic surgery; psychosocial impact; quality of life; *E-Cadherin* (*CDH1*); total gastrectomy; qualitative interviews

Introduction

Between 1-3% of gastric cancers are inherited, this includes Hereditary Diffuse Gastric Cancer (HDGC) (van der Post et al., 2015). Approximately 25% of cases of HDGC are caused by mutations in the *E-cadherin* gene (*CDH1*) (Guilford et al., 1999; Gayther et al., 1998; Fitzgerald et al., 2010). *CDH1* mutation carriers have an earlier than average age of disease onset (mean 38y; range 14-69y) (Kaurah & Huntsman, 2008) with cumulative risks of gastric cancer at 80 years of 70% in men and 56% in women (Hansford et al., 2015). Annual surveillance using endoscopy and/or chromoendoscopy plus multiple random biopsies is suggested for high-risk individuals (van der Post et al., 2015). Once the disease is invasive rapid progression makes it hard to achieve a cure (Fitzgerald et al., 2010; Terdiman, 2007; Lynch et al., 2005) therefore, prophylactic total gastrectomy (PTG) is recommended in early adulthood, normally, during the early to mid twenties (van der Post et al., 2015). PTG carries a 100% long-term morbidity risk (Kaurah & Huntsman, 2008) After-effects include: rapid intestinal transit, weight loss (>20% of body weight), dumping syndrome and diarrhea, iron deficiency anemia and osteoporosis, which may have serious physical and psychosocial *sequelae* (van der Post et al., 2015; Newman & Mulholland, 2006; Caldas et al., 1999).

The psychosocial implications of PTG are under-researched, including its impact on quality of life and how patients adjust post-surgery. Recent research suggests that global quality of life scores return to preoperative levels 12 months following PTG, although there is evidence of persistent problems with eating, abdominal pain and body image (Worster et al., 2014). Weight loss following PTG has on-going negative impacts on (men's) body image, may affect stamina and ability to work, and hence, may negatively impact on quality of life (Worster et al., 2014; Garland et al., 2011).

With the exception of Worster et al's (2014) quantitative study and a couple of case reports (e.g. Garland et al., 2011), there is very little published research on the psychosocial impact of undergoing prophylactic gastrectomy to manage one's inherited cancer risks.

Recent research on older (87% > 50 years) patients with upper gastrointestinal cancer suggests gastrectomy is associated with enduring eating and weight problems and financial difficulties >5 years post-surgery (Lee et al., 2014). In contrast, earlier research found that despite significant weight loss, there was little difference in cancer patients' overall quality of life scores nine years after therapeutic gastrectomy compared with normal controls (Tyrvaainen, 2008).

Patients have to eat little and often after gastrectomy, and these dietary changes can be experienced negatively (Fitzgerald et al., 2010; Worster et al., 2014; Garland et al., 2011; Carey et al., 2013). The ability to tolerate larger meal sizes while maintaining control over gastrointestinal symptoms is important for gastric cancer patients' long-term quality of life, (Liedman, 2001) while the loss of appetite and hunger following full/partial gastrectomy for gastrointestinal cancers is associated with feelings of grief, loss, frustration and anxiety (Carey et al., 2013; Mallstrom et al., 2013; Ollson et al., 2002; Clarke et al., 2011). Eating is frequently regarded as an obligation not a pleasure following gastrectomy (Ollson et al., 2002) and disruptions to former eating patterns may lead to former cancer patients avoiding social situations, which, in turn, increases anxiety and depression (Carey et al., 2013; Mallstrom et al., 2013).

While this earlier research provides some insight into the issues faced by those undergoing gastrectomy it is possible that cancer patients' responses to this type of surgery may differ from those of younger healthy patients who have chosen to undergo gastrectomy for prophylactic reasons, because of the formers' health status and because this group of patients is more likely to be of more advanced age. Given the difficulties of extrapolating the findings of studies of (older) cancer patients to (younger) healthy at-risk individuals, we are unsure about how to support those who are faced with the decision about whether or not to undergo PTG. The aim of this qualitative interview study was to determine the psychosocial implications of undergoing gastrectomy to manage the risks of HDGC.

Methods

The study was approved by Cambridge East Research Ethics Committee 14/03/2012 (Ref: 12/EE/0066).

Recruitment

A convenience sample of patients (>18 years) who had undergone PTG to manage their risk of HDGC were recruited from the Familial Gastric Cancer Study (FGCS) in the UK. All those who had undergone PTG and were on the register and who the Register Coordinator thought would not be distressed by receiving an invitation to participate were sent: an invitation letter from Consultant/Register Coordinator, information leaflet and an opt-out form to return to the researchers. If the recipient did not opt-out within three weeks, they were contacted to arrange an interview.

Data collection and analysis

Data were collected in open-ended face-face interviews by NH and SB. Interviews lasted between 1 and 3.5 hours (mode 100 minutes). On four occasions other family members were present. However, these were not joint interviews and in most cases the family members commented infrequently, sometimes providing factual corrections to the interviewee's narrative, and occasionally describing their role in supporting the interviewee pre and post surgery. All contributions were recorded with consent and informed the analysis. An inductive design was employed entailing simultaneous data collection and analysis. The interviews were based around a loose topic guide (see Table 1) that encouraged interviewees to focus on areas of importance to themselves. On-going analysis provided the basis for more targeted questioning in later interviews; in other words, as themes emerged within the interviews the emphasis and structure of the questioning changed in response and in subsequent interviews. The digitally-recorded interviews were transcribed. Transcripts were allocated pseudonyms, which are used in the reporting below, and were read and coded by members of the research team (NH, JL and SB). The method of constant comparison was used to develop a framework for indexing and analyzing the transcriptions (Strauss & Corbin, 1990), this enabled the identification of recurrent themes between and within the interviews (see Box 1). The analysis group discussed emerging

findings, which allowed for the redefinition of the coding framework. Data were examined for negative evidence to counteract the possibility of researcher bias. The analysis reported below focuses upon the processes of undergoing surgery and the impact of surgery on individuals' lives

Table 1

Findings

Twenty-nine FGCS participants who had undergone PTG were approached, two declined and 14 men and 13 women were interviewed. The age at which interviewees underwent PTG ranged between 19-64years (median 36y, mode 26y) For the purpose of this paper we define younger patients as those who underwent surgery under the age of 30 years; 37% of the interviewees were in this age group. This age cutoff was chosen because high-risk individuals are recommended to undergo PTG during their twenties. Interviews occurred 0.5-9 years postoperatively (median 3y). Interviewees had undergone PTG at different centers within the UK.

Table 2

The data suggest that PTG has a range of physical psychological, social and economic impacts, many of which were interlinked in interviewees' accounts. These overarching themes emerged from the analysis and involved grouping together a number of minor themes – for example: physical impacts includes the subthemes: managing dietary changes, living with fatigue, living with gastrointestinal symptoms, feeling fatigue, changes to eating and appetite (See Box 1). Before we discuss these we will present data on interviewees' experiences of undergoing surgery and their recovery more generally.

BOX 1 here

Undergoing surgery and recovery

Nearly all interviewees said that surgery and convalescence had not been as physically challenging as they had anticipated.

Angus: Within five, six months I was back working and I kind of felt fine. I've no regrets about this operation; I feel quite lucky that I got away with it, the operation and then the results of the operation, nowhere near as bad as I feared. 45yrs (age at surgery):3yrs (time since surgery)

However, age appeared to influence these experiences. The reports of younger interviewees suggested that this group recovered more quickly from surgery than the older interviewees.

Anna: I think being young as well I bounced back. I spent eight days in hospital and then I went back to my nana's for a few weeks and she looked after me. But I think I was really lucky in terms of how I recovered very very quickly. 21yrs:7yrs

Patrick: I were really struggling in my first year from having my stomach out and stuff. Um ... I had almost three lots of dumping, I had, er ... problems with my B12, my weight loss to struggling every day just to try to eat breakfast and... I don't have to be a tough man but there were times when just trying to eat a breakfast would bring a tear to my eye, because it were terrible. And I hated it because my wife could see it, and she couldn't do anything
58yrs:3yrs

Despite surgery and convalescence not being a problematic as most participants had expected, all described PTG as having a range of interrelated physical, psychological, social and economic impacts. The perceived force and duration of these impacts varied: a small group, mainly the younger or fitter interviewees, said their life had more or less returned to 'normal' a couple of years following surgery.

Larry: but looking back now I think where I am, and I think where my sister is, I think it hasn't really affected my lifestyle at all. I think maybe I thought it was going to have a bit more of an impact on my lifestyle but no, I think it hasn't really changed too much, like now it's under control. 22yrs:3yrs

However, this was not the case for everyone as others, including a couple of those who had undergone surgery during their twenties, said they were still coping with the social and physical aftereffects of surgery years later.

Ella: I can never do as much as I want to do in anything. And so I definitely have to consider my health these days, and my fatigue especially, when I make decisions about what to do.

Whereas before it just would not enter my mind. So I have to think well I just have to factor in rest, not do too much. 26yrs:6yrs

Likewise, Colleen, who had undergone PTG in her mid forties, described a number of physical problems she experienced since undergoing surgery 5 years ago, which had meant that she was now incapacitated and unable to work.

Colleen: I went ahead and had my stomach removed, and it's been quite horrendous ever since, really. And totally not how I expected to be. I was kind of expecting to be back at work after three months, probably four and sort of on the mend, and I think after three months I was at my lowest point because I couldn't see any improvement really from when I got out of hospital to, I think the day I come out of hospital I started having all this bile sickness, or the night before, and that has continued ever since. I still get that sort of on a monthly basis, and it can last anything from a week, and it has been known to last up to three... I've continued with dumping syndrome all the way through as well, so I can get the shakes and the dizziness and the nausea and the ... everything, the flushes, everything going to the toilet, everything to do with dumping syndrome. And I get very low energy, very tired...and not only that, it did bring all the grieving of [name of sister] and everything to light...it does change you as a person. 44yrs: 5yrs

Colleen's account of post-surgical life demonstrates the extent to which ongoing morbidity associated with PTG can impact on an individual's life. As suggested above, the short and longer term physical and psychosocial impacts of PTG appear to be mitigated or exacerbated, in part, by the timing of surgery; specifically the age at which one undergoes PTG. There was some evidence that those who had a PTG in their twenties found the after-effects easier to manage than those who had undergone surgery later in life. However, while the age at which interviewees underwent PTG may have had some effect on their response to surgery, there was little or no evidence that the time elapsed since surgery influenced interviewees' responses, although the data suggest that interviewees had learnt to adapt over time.

Physical impacts

Eating and appetite

All interviewees said their eating habits had changed permanently post-surgery and described having to relearn how, what and when to eat. All reported a loss of appetite, or hunger, and an inability to gauge fullness or satiation, the result being that eating post-surgery was no longer experienced as spontaneous and enjoyable, but, rather, as a regimented, planned and conscious activity.

Maya: I don't think that I feel hunger. ...I miss the flexibility of how I used to be able to eat, and it's something you kind of take for granted until it's taken away from you. I don't think I miss hunger pains, I miss being able to do what I like in terms of food. And eat what I like, and eat what portion size I like. 26 yrs:2 yrs

Many interviewees described eating as a necessity, not a pleasure, and this had social repercussions for some who said they no longer socialized around food. As Maya went on to say:

Maya: I used to go out with my friends we used to go out for lunch a lot, and I don't do that with my friends as much because I worry if I get sick, and then they're going to have to deal with me being sick 26 yrs:2yrs

Dietary changes

All interviewees talked about making dietary changes; however, there appeared to be no stereotypical post-gastrectomy diet. Indeed, there was a great deal of variation between interviewees with regards to the foodstuffs they could tolerate.

Lily: And I think the worst thing is, or the most difficult thing is, me and my sister are completely different what we can and can't eat,... I think that's the difficult thing, that there's no, there doesn't seem to be any rules on what you can and can't eat, it's what works for you. 23yrs:6yrs

Many talked about sticking to tried and tested foodstuffs that were easy to consume and digest.

Kay: You become quite lazy eating. Like I don't want to eat an apple because I have to chew it so much. I'll eat it if it's cut up, I'll cut up apples now, but I don't want to, I can, but I prefer to eat a banana because it's a lot easier to eat. 31yrs:8yrs

A few, like Alec, said they needed to eat large quantities of “unhealthy” foodstuffs to maintain their weight post-surgery, and worried about the impact of their diet on their (cardiovascular) health.

Alec: But there's one thing about getting your stomach removed, you can eat as much or what you like, chocolates, anything, you're not going to put weight on. I think it's a bad thing in some ways because [in] more recent years I've sort of worked out that "Alec, you could be getting unhealthily thin, you know, although you're thin, you could be getting unhealthy."

64yrs:9yrs

Gastrointestinal symptoms

Some interviewees reported ongoing problems with dumping, nausea and diarrhea following surgery. In most cases, these symptoms were experienced as manageable and as having little effect on other aspects of life

Keira: Just the dumping now and again, and the reflux. And I think the reflux has been the biggest problem because that's disturbed my sleep. ... with the reflux I am awake pretty much ... up to five times a night really. 23yrs:3yrs

Others said that their GI symptoms had a major impact on their ability to work and have a full social life.

Rani: ...it's uncontrollable diarrhea, basically, and if you're out it's absolutely awful and devastating. And that's another reason why it affects your social life because I feel like I've got to make sure whenever I go out I can get access to a toilet. I won't take the coach to travel anywhere because there's no toilets on the coach, I avoid public transport. 27yrs:2yrs

Feeling fatigued

Many interviewees, reported suffering from ongoing fatigue since their operation, which some, like Erica, attributed to their diet and their inability to consume or convert sufficient calories to maintain energy levels.

Erica: It's not tired how you feel, because everyone's saying, 'Oh it's because you're working and you've got [a son] and everything,' and it is like that, it is tiredness, but it's a different... So there are days when I just struggle to put one foot in front of the other. But that's only every now and again, I think it must just be everything just gets ... Because they say, don't they, your body's a machine, if you don't put the right stuff in you can't ... and if you're

burning off more than you're putting in. I mean when I was told in hospital that you had to eat high fat stuff and cream cakes and it's like a dieter's dream, but I don't, they don't agree with me, they make me very very poorly, so I don't eat them. They've suggested those compact meal, drinks things. So (Int: Have you tried them?) no not yet, they're in the cupboard! [Laughs]. But I mean I eat, I kind of eat a varied, I mean I still eat everything. I eat meat, fish, potatoes, I just don't eat a lot of it. That's all .Chocolate, biscuits, cakes, now and again. But then stuff like, then I know that I'm going to be poorly. So if you, if I'm poorly afterwards I'm not obviously getting it in me, it's just literally going all the way through.
35yrs:1yr

Fatigue was a chronic issue for a small group, particularly older interviewees (see Colleen above) and those in manual occupations, who had been unable to resume fulltime work post-surgery as a result. Nico's partner described how Nico (48yrs:8yrs), a builder, was no longer able to work full-time following the surgery because of his ongoing fatigue.

Nico's Partner: So [Nico] he'd been used to working five or six days, ten-hour days, eight-hour days, he was probably down to working 20 hours a week, I would say, realistically. A maximum of 20 hours a week. And if he was working he was doing nothing else. So if I'd come home from work and he'd been, come home from work at two o'clock he'd be in bed. So frequently I'd come home and you'd be in bed, wouldn't you? (Nico: Yeah) So that's the way he functioned. He couldn't go out in the evening, he couldn't do anything else, so his whole life was just ... doing enough to do that thing. And if he did something else, so if he went out with a friend walking, or to [place name] doing something, then he wouldn't work the next two days. That's how it worked in reality.

Psychological impacts

Relief of anxiety

On the positive side, all interviewees said that since undergoing PTG they no longer worried about their risks of developing gastric cancer.

Lara: It is quite a relief really, knowing that you've eliminated at least these things, but if we can take away those kind of things then it does put your mind slightly more at ease.
36yrs:4yrs

The relief of cancer anxiety was regarded as the major benefit of undergoing surgery, as Joe, who had originally postponed surgery until he received a positive biopsy, said: *"The operation for me was closure of one fear in my life. (37yrs:3yrs)*

Colleen: So I just like hope that I'm going to get better, and I hope that one day I am going to be able to go back to work and things will improve and I can get on a bit better than what I'm getting on now. And at the same time I think what keeps me, I'm here to see my grandchildren and [name of sister] isn't. Would you sooner be here and living a life like this and seeing your grandchildren or would you sooner have had like a quality of life or something and not, not be here and seen them? 44yrs: 5 yrs

Interestingly, although receiving a positive biopsy result was regarded as very influential when it came to decision-making about PTG, no differences were observed between those who underwent surgery following a positive biopsy and those who did not with regard to relief of anxiety.

Threats to identity

However, surgery was also described as precipitating a number of potentially worrisome identity changes. A few interviewees said that they felt like a different person following surgery.

Patrick: First year it were a struggle. I felt this terrible loss about my stomach. And like you suddenly think to yourself, where's four stone of me? Where is it? And I kind of like had to run my head round that, where it had gone, where I'd gone. Because I were feeling like overwhelmed by it all, so I just wanted to find me again. 58yrs:3yrs

Rosa: I was going to say I didn't feel normal for another year, but I don't think I'll ever feel normal now, to be honest, because ... it's always, it's always something that's there.... Because to look at me, I look normal. I think that's, that's one of the hardest things, people just don't get it. 26yrs, 6yrs

In many cases the interviewees described their identity as threatened because they could no longer do the things they had done before, namely, work, socialise, eat out, drink alcohol, play sport. As Boyd explained: *"Physically I can't do my marathons, I used to run*

marathons all the time, two or three a year, and I can't do them. And that really disappoints me." (45yrs:8yrs)

Body image changes

Many talked about how post-surgical weight loss had affected their body image. While a few said they felt positive about their post-surgical body:

Larry: I suppose around the time of the operation I was quite worried about sort of getting quite skinny and scrawny, but now like 24 months down the line I'm pretty happy with my body. 22yrs:3yrs

And some, like Anna, described the changes to their bodies caused by surgery as a positive reminder of their control over their risk: *"I kind of feel like proud of my scar because I know that I was given a chance to do something about stomach cancer."* (28yrs: 7yrs) Others, particularly the men we interviewed, described their weight loss and/or loss of muscle mass as having a negative impact on body image and their sense of masculinity. Joel, focussing on his weight loss commented that it made him look very different.

Joel: I'm not happy with my weight. It goes up and down, about ten-ten, ten-eleven. I'd like to be eleven-and-a-half. Which I don't think's too much to ask, but I'm really struggling to get above that now. I can't get, I really struggle to get above it. Because I still feel a little bit, because I was always quite a chunky, not chunky-chunky but I was always sort of pretty decent enough shape and that, and I feel very sort of, um, thin and skinny and a little bit scrawny now, I'm not happy with it so yeah, I'm having a little bit of an issue with that one at the moment. 36yrs:4yrs

Nico, described how he felt weaker and less fit since the surgery and thus, felt his body image as negatively affected by his perceived lack of bodily strength.

Nico: Because, um, physical strength now is, is not all gone but virtually all gone. You know, but, um ... it's one of my biggest bug-bears because I've always been extremely strong and extremely fit, right from a child all the way through. And that is difficult,...I never have been a thin. But I've always been, no it's not thin or fat with me, it's nothing to do with that, it's lack of strength. Yeah, that's the ... the thing. You know, I've always been a very, very strong person. And ... I'm not. I mean I could walk, even now I walk up to things that I would have picked up with, in one hand, and I ... I struggle moving it, you know. (Laughs) 48 yrs:8 yrs

Social impacts

Changing social and familial relationships

Many interviewees said that their fatigue, lack of finances, or an inability to eat as much or drink alcohol meant they could not easily socialize with friends (see Maya above) and this had affected their relationships.

Colleen: So it's had this huge impact on, it's led onto other things and a huge circle of things and it all stems from. And then the money side of it as well that has been horrendous, because I've not been able to work, so I've been on like sick pay and then they stop it, and then the government's changing it all and I have to go for interviews and, oh, it's, it's horrendous. It really is, because it although yes it's money and your health is more important and everything, but without money you can't do anything. Um, I've got a mortgage and everything and, you know, my flat and that, so it does have extra impact ... on being like this, and I think being long-term as well, it changes you ...social-wise, friends-wise and that, I think a lot of friends I've kind of lost through it, I don't think they can cope with it. Because I am ... I am a completely different person to how I was before. ...It does change you as a person. I think long-term it does affect you.... I am a completely different person to how I was before. And, they'll plan, or if you plan something to go out I can't go because I'm sick or something. I can't plan things because I'm up and down every half an hour, I don't know how I'm going to be until I walk out the door. 44yrs:5yrs

However, there appeared to be an age effect in this regard as many of the younger and fitter patients said that, after an initial period of adjustment, their social lives had returned to more or less “normal” once their energy levels increased and they learnt to adjust their eating habits.

A few interviewees also described PTG as having a negative impact on intimate relationships. Some younger interviewees worried they would be unable to find an intimate partner who would be able to understand their health needs.

Rani: that's another thing with like getting into a new relationship with someone, it's like, oh I've got to explain all that (laughs). I'm always worried about explaining it and someone getting put off by things. 27yrs:2yrs

Others, who were in relationships, said that their sexuality had been negatively affected by surgery. Nico: *"[PTG] affected us [himself and partner] in quite a big way. ...our sex life has gone, more or less completely....."* (48yrs:8yrs)

PTG also affects familial relationships, and many interviewees described how intimate partners and other family members had become their carers in the post-surgical period. Many interviewees talked about the sheer hard work demanded of relatives who had supported them post-operatively, and described how they had to rely upon partners and/or parents during convalescence.

Nathan: *And then with my wife so I've been very fortunate..., because if you've not got support, especially at home, I tell you, I don't know where I'd be now.... If anybody's thinking of having this operation, you've got to think long and hard about that support that is available to you.* 41yrs:1yr

A few interviewees said that watching someone go through this procedure and the effect it has on their life had had a major emotional impact on their relatives, particularly parents who may have lost their partner to gastric cancer. Sylvia, talking about the effect her surgery had had on her husband, commented *"to then deal with another family member that's gone through the preventative course of action is very hard emotionally on the loved ones."* (41yrs:3yrs)

Economic impacts

Costs of convalescence

A significant group of interviewees described PTG as having negative financial consequences in the short to medium term. This included debts they had incurred since undergoing surgery. Some self-employed interviewees said they had gone into debt because they could not access welfare payments during their extended convalescence. A group of younger interviewees said they felt that taking time out for surgery and convalescence in their early 20s would have economic implications in the longer term, because this was a time when they felt they should be working and/or studying to consolidate their career.

Maya: it's more in terms of occupation and work and things because I've been put back a lot in time, like being 28 and just starting my Master's now, I've lost a lot of time that I can't get back. 26yrs:2yrs

Physical costs have economic implications

Many interviewees, in all age groups, said they had struggled financially since surgery because they could no longer continue working (full-time), either because of chronic gastrointestinal symptoms or fatigue.

Nico: Finances is a big, big thing, when you've got a problem with being able to earn and in my trade, and with my skills, and at my age, you lose a massive amount. I've been turned down for jobs that I could do standing on my head. I was just trying to find a simple, easy little job that I could maybe do, like a caretaker or something like that. 48yrs:8yrs

Fatigue was a particular problem for (older) manual workers, as either it meant that they could no longer work, like Nico, above, or anticipated that they would be too tired to continue working long-term and therefore, would have to take early retirement or become unemployed:

Joel: I fear that I won't be able to do the job that I do in future, because I'm not going to be any fitter than I am now. I do worry because I get tired obviously, because I don't eat enough, And in the future I do worry. I've tried looking at other jobs, going in other directions. It's very very difficult at my age to change what you've been doing for the last, well for the last 15 years. 36yrs:4yrs

It was not only the older interviewees who reported problems with fatigue, some of the younger interviewees, who worked in sedentary occupations, described how fatigue had prevented them returning to work full-time. Finally, a small group said their weekly expenditure had increased because they now needed to eat different and more expensive foodstuffs

Discussion

This is one of the first and largest in-depth studies to look at the psychological, social, economic and physical impact of undergoing PTG to manage the risk of HDGC. Although the

benefits of risk reduction were widely acknowledged as outweighing the costs of surgery by our interviewees, in a few cases negative *sequelae*, particularly, chronic fatigue, dietary restrictions/changes and gastrointestinal aftereffects, were experienced as extremely debilitating and adversely impacting on quality of life in various interrelated ways. There was evidence that the impact of PTG varies according to age, with younger and fitter interviewees generally describing their recovery as quicker and some surgical aftereffects as more transient or as having less of an effect on their social and economic lives.

Surgical resection of the stomach has a major and on-going nutritional impact [van der Post et al., 2015; Fitzgerald et al., 2010], which was reflected in participants' accounts. The data indicate that PTG affects diet and eating in various ways including: loss of appetite and hunger, loss of spontaneity in food consumption, an inability to tolerate certain foodstuffs and, thus, resulting difficulties socializing around food; similar findings have been reported in studies of cancer patients undergoing surgery for upper GI cancers (Carey et al, 2013; Mallstrom et al, 2013; Ollson et al., 2002; Clarke et al., 2011; Wainwright et al., 2007). However, in contrast to some of these earlier studies, only a very few of our interviewees reported feelings of social alienation as a result of the dietary changes they had had to make following surgery, however, many said that PTG had required them to make a number of adaptations to their social lives which they found difficult, not least, because this had negatively impacted on their identity.

Surgery was reported as having a number of psychological impacts. Primarily, it removes anxiety about the risk of cancer and, in this respect the effect of undergoing PTG can be seen as similar to risk-reducing mastectomy and oophorectomy (Hallowell et al., 2012). However, in addition to this very positive effect, PTG was also described as having a negative impact on body image and personal identity. Garland *et al.*, (2011) recently speculated that there may be gender difference in the impact of total gastrectomy on body image. This was confirmed in the current study, as there was evidence that male

interviewees experienced weight loss/loss of muscle mass as negatively affecting body image and feelings of masculinity (Worster et al., 2011; Garland et al., 2011; Ollson et al., 2002). Other observed impacts on identity related to the fatigue that many interviewees experienced and which affected their ability to work and socialize at pre-surgical levels. Similar social impacts have been observed in cancer patients undergoing upper GI surgery, who describe their personal identity and self-esteem as negatively affected by their inability to continue working (Clarke et al., 2011).

Upper GI surgery is reported as having a negative financial impact on older cancer patients (Clarke et al., 2011; Lee et al., 2014). Many of our interviewees similarly suffered financially following surgery with older interviewees and those working in manual occupations, in particular, reporting an inability to work (full-time) because of increased fatigue post-surgery. The data also suggested that undergoing surgery in early adulthood is perceived as impacting on future employment opportunities. These observations suggest there is a need for more systematic prospective research to explore the socioeconomic impacts of PTG over time.

Strengths and limitations

This study included a large sample of patients who underwent PTG at different ages and at different times, and this allowed us to consider the effects of age and recovery/adaptation over time. While there was the suggestion of an emerging trend in the dataset, primarily the effect of age on adaptation to PTG, there was also a lot of variation suggesting there is a need for systematic longitudinal research, which looks at the effect of age and time on individuals' response to PTG. Indeed, it can be argued that fact that our interviewees had undergone surgery at any time over the last decade was a limitation of this study because the treatment and counseling of this patient group in the UK has changed during this period (van der Post et al., 2015).

The identification of the influence of age on post-surgical response as a cross cutting theme within this dataset raises a question about the degree of data saturation obtained in these interviews (Strauss & Corbin, 1990). As noted above, this project involved a convenience sample of participants from the FGCS. While we acknowledge that further recruitment would have allowed us to categorically state that data saturation was achieved, at least as far as the impact of age on response to surgery was concerned, unfortunately we were not in a position to do this as we had approached all the available eligible patients during the period of data collection. This limitation serves to further emphasize the need for prospective research to clarify the role of age on response to PTG.

Clinical Implications

High-risk individuals who are facing a decision about how to manage their genetic risks of HDGC need clear information about PTG and its after-effects (Garland et al., 2011; Clarke et al., 2011). They need to know that the outcomes are difficult to predict and that, although this procedure may serve to preserve life in the longer term, it may have negative psychological, social and economic impacts. Individuals who are considering PTG therefore, need to prepare for significant life changes post-surgery and thus, may benefit from discussing the impact of surgery, not only with genetic counselors and other healthcare professionals, but also with those who have already undergone this procedure (van der Post, 2015; Clarke et al., 2011). However, for these discussions to be of maximum benefit, we suggest that potential patients should be matched with former patients according to gender, age, life stage and occupation where possible, as our data suggest that the experiences of younger people may differ from those who undergo surgery later in life. However, in making this recommendation we are aware that, as observed above, the impacts of surgery are highly variable, and suggest that in order to avoid potential surgical patients hearing someone's "idiosyncratic" story they should be encouraged to contact a number of patients who have had different outcomes and experiences.

Like earlier studies of cancer patients who have had upper GI surgery, (Mallstrom et al, 2013; Ollson et al, 2002, Wainwright et al, 2007) our interviewees talked about the need for support around eating and diet. However, although all interviewees talked about the dietary changes they had had to make, there appeared to be no stereotypical post-gastrectomy diet. Arguably, patients undergoing PTG need to be made aware of this variation and encouraged to try a range of foodstuffs to determine what they can personally tolerate. Our data, like others', emphasize the need for personalized post-surgical nutritional plans (van der Post, 2015; Ollson, 2002; Wainwright et al., 2007).

Finally, while some individuals' lives remain relatively unchanged by PTG, the majority needs to manage the effects of PTG well into the future. Thus, we recommend that pre-surgical counseling should emphasize the fact that, for many patients, PTG is experienced as "an ongoing journey" and should not be seen as a quick fix.[Carey et al., 2013:2754] Indeed, we would argue that genetic counselors have a major role to play in helping patients who are considering PTG to anticipate and identify their potential short- and longer-term support needs.

Conclusion

In conclusion, this study demonstrates that the physical impacts of PTG, for example: changing food tolerances, changes in bodyweight, on-going GI symptoms and fatigue have a number of interrelated psychological, social and economic consequences. PTG can be seen as an uncertain procedure, disrupting life in the short, medium and, potentially, the long-term, however, it removes the risk of developing stomach cancer and, thus, is experienced as both a life-altering and life-saving procedure.

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Conflict of interest

The authors declare they have no conflict of interest.

Informed consent

Informed consent was obtained from all individual participants included in the study.

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Table 1: Interview topic guide

Demographic details

Narrative about Cancer in family and self, - Can tell me your story about the cancers in your family – what happened , when where- (how did you find out about risk what have you done about it and why)? ***Pick up threads in narrative***

Family and personal history

- Experiences of cancer in family
- Views of own and others' risk
- Genetic testing – why/why not
- Screening why/why not

Surgery

- Influences on surgical decisions - who involved, when, why, what
- Surgery and convalescence
- Feelings and experiences - Pre/post-surgery
- Impacts: health, eating, sociality, risk perception, work, identity, relationships

Information needs

- Information provided – good/bad
- What more information would you have liked
- What would you tell others considering these procedures

Family

- Experiences , views
- Communication about results and decisions
- Risk perceptions

Table 2: Participants' characteristics

	N	%
Gender		
Women	14	52
Men	13	48
Age at surgery		
<30 years	10	37
31-40 Years	6	22
41- 50 years	7	26
>51 years	4	15
Years since surgery		
<12 months	1	4
1-3 years	13	48
4-6 years	7	26
7-9 years	6	22
Mutation status		
confirmed	24	89
unconfirmed	3	11
Positive biopsy pre-surgery		
yes	13	48
no	14	52

Box 1: Thematic structuring of data analysis

Physical Impacts

- Managing dietary changes
- Hunger and appetite
- Living with gastrointestinal symptoms
- Feeling fatigue

Psychological Impacts

- Relief of anxiety
- Threats to identity
- Body image changes

Social Impacts

- Changing social and familial relationships

Economic Impacts

- Costs of convalescence
- Physical costs have economic consequences