

Original Article

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Corresponding author: Luca Ghirotto;
Email: luca.ghirotto@ausl.re.it

Defining a balance by compromising with fear: A grounded theory study on returning to eating after a total gastrectomy

Licia Baldi, ^{M.D.}¹, Marco D'Inca, ^{M.D.}¹, Jürgen Wildner, ^{PH.D.}², Francesca Tecce, ^{M.P.T.}³, Romina De Pasca, ^{R.N.}⁴, Stefano Finotto, ^{R.N., M.Sc.}⁵, Matías Eduardo Díaz Crescitelli, ^{R.N., PH.D.}⁶ , Silvia Di Leo, ^{M.PSY., R.P.}⁷ and Luca Ghirotto, ^{PH.D.}⁶ 

¹Oncological Medicine, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy; ²Department of Primary Care, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy; ³Azienda Sanitaria Locale di Avellino, Avellino, Italy; ⁴Medical Directorate, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy; ⁵Department of Surgery, Medicine, Dentistry and Morphological Sciences, University of Modena and Reggio Emilia, Pad. De Sanctis, Reggio Emilia, Italy; ⁶Qualitative Research Unit, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy and ⁷Psycho-Oncology Unit, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy

Abstract

Objectives. Gastric cancer patients undergoing total gastrectomy face nutrition-related complications and worsening quality of life after surgery. In this context, gastrectomized cancer patients are required to cope with new conditions. Little is known about their accommodating feeding to the new life condition as a negotiated process among stakeholders in real contexts. This study aimed to investigate the shaping of this process as influenced by the perspectives of patients, health-care professionals (HPs), and caregivers (CGs).

Methods. A constructivist grounded theory study, through semi-structured interviews and interpretative coding, was designed to answer the following research question: “what is the process of returning to eating and feeding after a gastrectomy?”

Results. The final sample included 18 participants. “Defining a balance by compromising with fear” is the core category explaining returning to eating as a process negotiated by all actors involved, with patients trying to find a feeding balance through a multi-layer compromise: with the information received by HPs, the proprioception drastically altered by gastric resection, new dietary habits to accept, and complex and often minimized conviviality. This process involves 4 main conceptual phases: relying on the doctors' advice, perceptive realignment, rearranging food intake, and food-regulated social interaction. Those categories are also shaped by the fear of being unwell from eating and the constant fear of tumor relapse.

Significance of results. Multiple actors can meet patients' and their CGs' nutritional, care, and psychosocial needs. A multidisciplinary approach involving nutritionists, psychologists, occupational therapists, social workers, and anthropologists can be key to effectively managing these patients' survivorship care. We suggest training all the professionals on the first level of nutritional counseling.

Introduction

Gastric cancer (GC) is a fatal disease with poor overall survival statistics worldwide (Sexton et al. 2020). Although it is steadily declining in incidence (Rawla and Barsouk 2019), GC is the fifth most frequent type of cancer and the third-leading cause of cancer-related death worldwide (Bray et al. 2018). GC is the fourth most common cause of cancer deaths in men (Fitzmaurice et al. 2019) and the seventh most commonly occurring cancer in women (Sexton et al. 2020).

GC preferred treatment is surgical (Bollscheweiler et al. 2014), namely tumor resection, in multimodal therapy (Agnes et al. 2020), especially for early-stage disease (Sexton et al. 2020). Total or subtotal gastrectomy with D2-lymphadenectomy is the standard treatment for early GC with suspected lymph node metastases (Bollscheweiler et al. 2014). For pathological stages II and III, total gastrectomy is performed with preoperative and adjuvant chemotherapy, improving overall survival for elderly patients (Wakahara et al. 2018).

Even if it provides the only hope for long-term survival (Papenfuss et al. 2014), gastrectomy is aggressive and causes postoperative complications. Nutrition-related complications (including weight loss, food intolerances, and micronutrient deficiencies) are common (Rogers 2011) and result in long-term survivors' low quality of life (QoL) after gastric resection (Gharagozlian et al. 2020). In this context, gastrectomized cancer patients (GCPs) are required to cope with new conditions. As elsewhere shown (Malmström et al. 2015), barriers in the patients' new life

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situation concern mainly nutrition and diarrhea in their role in impacting their physical health (Kobayashi et al. 2011) and social and emotional functioning. The lifestyle strongly changes (Khin et al. 2018), with gastrointestinal symptoms not improving (Carrillo and Santamaría 2019) and, consequently, QoL impaired (Conroy et al. 2006). In this context, it has been noted how patients experience bodily estrangement and reduction in feeding (Carrillo and Santamaría 2019), with the risk of physical decline (O'Neill et al. 2018). While the literature on dietary and nutrition perceived changes, given the long-lasting physical effects of gastrectomy, has recently increased (Bennett et al. 2020; Cipriano-Crespo et al. 2021b; Garland et al. 2011), research examining how GCPs adapt to their new life condition through dietary changes has predominantly emphasized physiological requirements from a medical and nutritional standpoint (Rosania et al. 2016). This focus has primarily centered on the GCPs' viewpoint while giving less consideration to the roles of family members, professionals, and the real contexts.

This approach has often overlooked the significant sociocultural and psychological aspects of food consumption and dietary choices. While a total gastrectomy undoubtedly has physical implications, like changes in digestion and absorption (O'Neill et al. 2018; Rupp and Stengel 2021), it is crucial to acknowledge that nutrition transcends mere physical consumption in a general context and specifically for these patients. Food profoundly affects human emotional, psychological, and social well-being. This perspective aligns with Lupton's observation that food-related actions, including buying, preparing, and consuming, are central to cultural integration, imbuing the symbolic dimensions of food with emotions and significance (Lupton 1996).

Individuals often have strong emotional connections to food, which affect their eating behaviors (Bisogni et al. 2002; Contento 2008). The emotional aspect becomes notably significant as individuals recover from a total gastrectomy and adjust to a new eating routine. Family interactions, cultural conventions, and expectations influence what and how patients consume (Lupton 1996). Furthermore, health-care professionals (HPs) play a role in guiding patients in navigating their dietary decisions (Taleghani et al. 2021).

Recognizing these dimensions of nutrition led us to understand that "returning to feeding" constitutes a psychosocial process in which various individuals collaborate and negotiate perspectives and meanings. Accordingly, this study aimed to investigate the shaping of such a negotiated process as influenced by the perspectives of GCPs, HPs, and family members/caregivers (CGs) to provide specific information for HPs and providers to help patients-families manage survivorship. A deeper understanding of this psychosocial process, including nutritional care and psychosocial needs, would be beneficial in improving the quality of care and ultimately contributing to better nutrition, health, and overall well-being outcomes.

Methods

Research design

A constructivist grounded theory (CGT) study (Charmaz 2014), through semi-structured interviews and interpretative coding, was designed to answer the following research question: "what is the process of returning to eating and feeding after a gastrectomy?"

CGT is a research methodology that develops theories based on reality's subjective and socially constructed nature. At its core, constructivism applied to GT acknowledges the dynamic and

subjective nature of reality (Bryant 2007; Charmaz 2014, 2017). It posits that reality is not an objective entity but is socially and subjectively constructed. This is a fundamental departure from traditional, positivist research paradigms, which view reality as something that can be independently observed and measured (Aldiabat and Le Navenec 2011; Tarozzi 2020). In CGT, human experiences and their meanings are context-dependent and influenced by social, cultural, and individual factors. CGT follows a systematic process of theory development grounded in the data collected during the study. It aims to generate theories that emerge from the data rather than imposing preconceived ideas.

The fundamental features of CGT encompass purposeful, non-random sampling, wherein researchers deliberately choose participants capable of offering varied and insightful perspectives on the research question. This sampling process remains dynamic and adapts as data collection and analysis advance. At the heart of CGT lies the pivotal technique of constant comparative analysis, primarily accomplished through the iterative coding process, which evolves from open coding through focused coding and culminates in theoretical coding involving increasing abstraction. Researchers systematically compare new and existing data to identify patterns, concepts, and categories. This iterative process continues until theoretical saturation is achieved (Morse 2004).

By implementing a CGT study, we could gain a more profound understanding of the psychosocial aspects of nutrition, recognizing that food intake is a process negotiated among multiple actors and influenced by various contextual factors. This approach helped us move beyond the surface-level understanding of patient experiences and enables us to unearth the nuanced ways in which they navigate the challenges of their journey. CGT equipped us with the tools to comprehend GCPs' experiences of returning to feeding after a total gastrectomy as shaped by their unique perspectives and social interactions with CGs and HPs.

Setting and initial sampling

The recruitment setting was the oncology ward of the Azienda USL – IRCCS of Reggio Emilia (Italy). We performed the initial and theoretical sampling (Charmaz 2014). The principal investigator, LB (oncologist), selected and contacted GCPs meeting the following inclusion criteria: patients who underwent total gastrectomy for at least 6 months up to 5 years or at the end of adjuvant chemotherapy treatment; their CGs; and HPs involved in the care process.

We contacted 11 GCPs (3 patients refused to participate), 2 CGs, and 2 HPs for initial sampling.

Data collection, data analysis, and theoretical sampling

We preplanned 3 different semi-structured interview guides for data collection according to participant types (GCPs, CGs, and HPs) without applying any theoretical framework (Table 1). LB, MDI (oncologist), JW (nurse), RDP (nurse), and FT (physiotherapist) interviewed accepting participants. No preexisting relationship existed between the interviewer and the participants. The data collection was performed from October 2017 to February 2018. Before, all the interviewers were trained in qualitative research methodology by LG (qualitative methodologist) and SDL (psychologist, expert in research methods).

Interviews were recorded and verbatim transcribed. We also collected participants' sociodemographic data. Participants were

Table 1. Interview guide

HPs	CGs	GCPs
<i>Introduction</i>	<i>Introduction</i>	<i>Introduction</i>
The interviewer thanks the participant and asks some ice-breaking questions, clarifying and explaining the study. Exemplifying question: “As you assisted these patients, we would like to understand your thoughts concerning what you did in this situation.”	The interviewer thanked the participant and asks some ice-breaking questions, clarifying and explaining the study. Exemplifying question: “As anticipated, the patient indicated you as an intimate person. We would like to understand your thoughts concerning the situation you are experiencing.”	The interviewer thanks the participant and asks some ice-breaking questions, clarifying and explaining the study’s aim. Exemplifying question: “As anticipated, we would like to understand your thoughts concerning the situation you are experiencing.”
<i>Health situation – the experience of health-care professionals</i>	<i>Health situation</i>	<i>Health situation</i>
In this thematic area, we intend to explore the assistance given to patients’ and professionals’ experiences. Exemplifying questions: “Do you remember patient N? Could you please tell me how the situation of N was? What approach do you have with a gastrectomized patient in follow-up? How do you feel about assisting this type of patient?”	This theme explores what the caregiver is experiencing concerning the gastrectomy his/her loved one underwent. Exemplifying questions: “Could you please tell me how it is going? How are you? How do you live the situation now? What do you feel? What thoughts do you have, concerning the health of your loved one?”	This theme explores what the patient is experiencing concerning the gastrectomy she/he underwent. Exemplifying questions: “Could you tell me how you are right now? Could you tell me how you live the situation now? What do you feel? What thoughts do you have?”
<i>Relationship with food</i>	<i>Relationship with food</i>	<i>Relationship with food</i>
This area investigates how professionals contribute to shaping patients’ relationships with food. Exemplifying questions: “Do you feel prepared about advising on food and dietary choices? Could you please tell me what you refer to patients? Could you please give me an example? What are your sources?”	We intend to explore the interviewee’s approach to food in this area. Exemplifying questions: “How is eating food at home? Could you please tell me your habits? Has anything changed since before? Can you tell me how you choose foods?”	We intend to explore the interviewee’s approach to food in this area. Exemplifying questions: “How is eating food? Could you please tell me your habits? Could you tell me how you choose foods? Could you tell me what you ate before the surgery and what you eat now? Is there anything missing? How do you live this thing?”
	<i>Organization and family management</i>	<i>Organization and family management</i>
	We intend to explore which strategies are implemented among caregivers and loved ones. Exemplifying questions: “What happens at home compared to buying and preparing meals? Who decides what to eat? Who prepares it?”	We intend to explore which strategies are implemented at home. Exemplifying questions: “What happens at home compared to buying and preparing meals? Who decides what to eat? Who prepares it? Could you please tell me what happens when you have to do the shopping?”
<i>Communication – information</i>	<i>Communication – information</i>	<i>Communication – information</i>
We explore the professionals’ point of view regarding communication and information exchange among them and patients/caregivers. Exemplifying questions: “Could you please tell me what questions you usually receive? What is the information you are asked for? How do you address these questions? What types of problems do patients expose to you? What about patients’ body weight? How do you manage body weight-related information?”	We investigate the family-health relationship during the follow-up and information needs. Exemplifying questions: “Do you now accompany the patient to oncological follow-up? Did it happen to talk to someone about eating? Compared to the information you received, how did it go?”	This area investigates the patient-health professionals’ relationship during follow-up and the information-related behaviors regarding food. Exemplifying questions: “Who follows you during follow-up? Are there other professionals involved? Regarding food, what do you discuss with physicians? What dietary recommendations did you receive during your journey? How did you find it? Could you please give me an example? What about the information you received?”
<i>Conclusion</i>	<i>Conclusion</i>	<i>Conclusion</i>
The interviewer thanks the participant and asks if there are any further thoughts to share.	The interviewer thanks the participant and asks if there are any further thoughts to share.	The interviewer thanks the participant and asks if there are any further thoughts to share.

allowed to read and comment on transcriptions, but none of them did it.

We concurrently collected and analyzed the data analysis in compliance with CGT (Charmaz 2014). The analysis entailed three phases of increasing abstraction: open, focused, and theoretical coding. LB, MDI, JW, RDP, and FT labeled data segments for generating conceptual codes during open coding. LG, MEDC, and

SDL revised the codes by discussing them with the team. During focused coding, analysts grouped the codes and interpreted provisional categories ($n = 15$). After focused coding, we theoretically sampled further participants for constant comparison among cases and saturating some emerging categories (*Groping in the dark; Giving and accepting suggestions; Weight as a measure of well-being; Coming to terms with the lost food; and Food-regulated social*

interaction). We involved 4 GCPs (1 died during the research) and 3 HPs. The interviews consistently changed according to category saturation needs. For example, brief interviews were conducted with HPs to achieve saturation in the “*Groping in the dark*” category. The primary objective of these interviews was to validate or refute the emerging conceptual explanation. The interviews consisted of 3 straightforward questions, including inquiries about the sources these professionals relied on, their level of preparedness, and their recommendations to GCPs. Regarding the “*Weight as a measure of well-being*” category, explorations were directed at GCPs and HPs. These questions aimed to explore whether weight was perceived as a valid indicator of health.

During theoretical coding, we reduced the categories and specified their relationships. Data collection ceased when the properties and characteristics of categories were also confirmed by the last data (theoretical saturation) (Conlon et al. 2020).

Rigor and validity

At least two researchers conducted every data collection and analysis step. Interviewers reported memos for each interview, allowing the research team to take the codes apart and analyze their meaning within the interview context. Team consensus-building discussions enhanced the findings’ trustworthiness. According to Charmaz’s validity criteria (Charmaz 2014), we adopted strategies for ensuring study credibility, originality, resonance, and usefulness. Credibility was achieved by collecting adequate data across all cases to substantiate the conceptual model. We used participants’ words as much as possible during the coding process for originality.

Regarding resonance, theoretical saturation gave us an overall picture of the process. Regarding utility, this study may offer a consistent interpretation of how GCSs return to feeding, providing helpful evidence for clinicians. We reported this qualitative research according to the Consolidated criteria for REporting Qualitative research (COREQ) checklist (Tong et al. 2007).

Ethical considerations

The Provincial Ethics Committee of Reggio Emilia approved the study (in-house protocol n. 71410 of 2017/08/03). The research was conducted following ICH E6 Guidelines for Good Clinical Practice and the principles of the Declaration of Helsinki. All participants signed informed consent containing information about the study aims and procedures.

Results

The final sample included 18 participants: 11 GCPs, 2 CGs, and 5 doctors (whose characteristics are reported in Table 2). Sixteen interviews were conducted (2 GCPs requested the presence of their CGs). The interviews lasted between 4’ and 35’ (20’ mean).

Defining a balance by compromising with fear

Returning to eating involves GCPs, their CGs and HPs in a process we conceptualized as “defining a balance by compromising with fear,” which is the core category. The conceptual coding highlighted that returning to eating causes many worries in GCPs who, through phases, managed to reach a feeding balance, which did not free

Table 2. Participants’ characteristics ($n = 18$)

Code	Participant	Age	Gender	Work	GC TNM – stage	Time since gastrectomy (at the time of the interview)	Sampling
P_01	Patient	65	Female	Housekeeper	T3 N2 – III	5 years	Initial
CG_01	Caregiver	67	Male	Retired	/	/	Initial
P_02	Patient	46	Male	Pizza chef	T2 N0 – I	1 year	Initial
P_03	Patient	54	Male	Worker	T2 N1 M0 – IIA	3 years	Initial
P_04	Patient	68	Male	Retired	T1 N3 M0 – IIA	4 years	Initial
CG_02	Caregiver	65	Female	Retired	/	/	Initial
P_05	Patient	78	Male	Carpenter	T3 N0 M0 – IIB	5 years	Initial
P_06	Patient	69	Female	Housewife	T3 N0 M0 – IIB	2 years	Initial
P_07	Patient	71	Male	Retired	T3 N3 M0 – III	4 years	Initial
HP_01	HPs	54	Female	Oncologist	/	/	Initial
HP_02	HPs	50	Male	Surgeon	/	/	Initial
HP_03	HPs	65	Male	Family doctor	/	/	Initial
P_08	Patient	82	Male	Retired	T3 N1 M0 – III	4 years	Theoretical
P_09	Patient	75	Male	Retired	T3 N1 M0 – III	2 years	Theoretical
P_10	Patient	71	Male	Retired	T4 N1 M0 – III	2 years	Theoretical
P_11	Patient	51	Female	Housewife	T4 N0 M0 – IIB	2 years	Theoretical
HP_04	HPs	42	Female	Oncologist	/	/	Theoretical
HP_05	HPs	58	Male	Surgeon	/	/	Theoretical

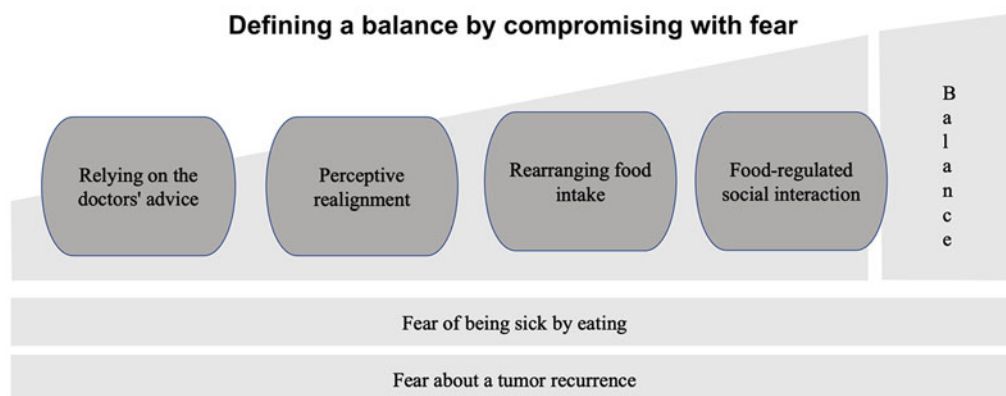


Figure 1. “Defining a balance by compromising with fear” conceptual model.

them from fear (about being sick from eating and possible tumor relapse). This process involves four main conceptual phases: *relying on the doctors' advice*, *perceptive realignment*, *rearranging food intake*, and *food-regulated social interaction*.

After initial moments of intense disorientation concerning what to eat and how, participants decided to rely on the HPs' advice, which was initially considered helpful. However, these did not provide effective strategies in the long run. GCPs began to listen to their bodies as a strategy to return to eating by trial and error. At this stage, weight proved very important to measure one's well-being, although HPs and CGs tried to relativize this. Achieving balance involved reorganizing eating not only in terms of quality and quantity of food but also in terms of modality. At this phase, GCPs began to accept their eating style, coming to terms with the foods they used to eat. Finally, returning to eating after gastrectomy impacted sociality. Conviviality as a crucial relational element for GCPs and CGs was strongly regulated by the balance found, the physiological limits imposed, and shame. For these reasons, social functioning appeared impaired. In sum, the balance the participants defined resulted from multiple compromises negotiated with their HPs and CGs. This process is visually rendered in [Figure 1](#).

We show the phases and categories with exemplifying quotations in [Table 3](#).

Relying on the doctors' advice

After the gastrectomy removed a “sick organ,” deputed to nutrition, our participating patients relied on HPs to clear doubts and obtain information regarding food. At the beginning of our process, GCPs collected suggestions regarding dietary recovery but reported a sense of *groping in the dark*. A second category explaining this phase is conceptually defined as *giving and accepting suggestions* since GCPs, with their CGs' support, decided to rely on HPs' advice and give them a chance.

Groping in the dark

GCPs welcomed the HPs' information, but the feeling of insecurity related to “how and what” to eat appears in common. As to information received, however, the informational efforts of HPs (surgeons) were perceived by patients as reassuring. GCPs reported that conversations with surgeons had been geared toward gradually eating all foods consumed before surgery. However, GCPs said that they would have preferred to receive written directions with lists of foods that they could or could not eat right away in some cases.

In this regard, patients who reported having consulted with family doctors recognized them as reference figures for food issues. CGs in this phase supported the patients by reiterating and reminding their loved ones of the information given by the HPs. However, the lack of trained and specialized HPs (e.g., a nutritionist) triggered the feeling that a GCP named “like groping in the dark.”

Giving and accepting suggestions

In uncertainty about the future diet and relapse, the advice received in the treatment pathway remained the primary source of information and reassurance, even after some time (within 5 years). Participants sometimes felt that the information they received from HPs was clear and sufficient. HPs, on the other hand, provided information that was not perceived as specific to their condition but common sense, i.e., splitting meals, preparing small portions, chewing for a long time, taking non-carbonated liquids, and away from meals.

Perceptive realignment

GCPs reported that they had implemented the advice of the HPs. They found themselves coming to terms with their daily lives and testing the information they received with the responses they got from their bodies. In this phase occurs what we have named “perceptual realignment” as the GCPs, also supported by the CGs, had to re-learn to live inside a different body with modified functionalities. The GCPs have learned by trial and error what foods to eat (*back to feeding by trial and error*), and as a measure of their well-being, they have focused on weight control (*weight as a measure of well-being*).

Back to feeding by trial and errors

The discovery of their body's new signals was an essential phase for GCPs as they began to measure themselves against the progressive reintroduction of the various foods to which they were accustomed. All GCPs reported experiencing the onset of post-prandial malaise with diverse abdominal symptoms. This led, in many cases, to feelings of nausea and even episodes of vomiting. The GCPs reported repeated attempts to find adequate amounts of the various foods and types accepted by their bodies. This trial-and-error process eventually led to the ability to formulate food and meal pairings to their satisfaction. It is important to note that, on the one hand, the patients quickly achieved consistent ways of “how” to feed themselves. However, patients felt an ongoing fear

Table 3. Phases, categories, and participants' exemplifying quotations

Phases	Categories	Exemplifying quotations
1. Relying on the doctors' advice	<i>Groping in the dark</i>	"But for eating, they do not tell you what to eat! I would have liked, to say, a written chart." (P_06)
		"And now that I have no stomach ... how am I supposed to eat? [...] I was not followed by a Nutritionist." (P_07)
		"The doctor at Oncology prospected me for changes in nutrition." (P_09)
	<i>Giving and accepting suggestions</i>	"I never asked my family doctor anything ... I followed what they told me in the hospital." (P_02)
		"Where I go for checkups, they always told me that I can eat anything. They said, 'slowly you will feel what will bother you ...'" (P_03)
		"The surgeon explained to me well: 'you can eat everything; however, I recommend a forkful, then go around the house, then another forkful' ..., but I cannot memorize them." (P_04)
		"The family doctor was very helpful." (CG_01)
		"They told me to eat ... have small meals and eat five, even six times a day. My doctor helped me a lot." (P_06)
		"My primary care physician would tell me how I should eat and how I should not eat." (P_07)
		"They helped me a lot with my behavior and, to this day, those things they told me serve me well ..." (P_10)
		"I advise patients to feed themselves little but often." (HP_01)
		"I always advise against carbonated drinks." (HP_02)
		"I always explain that if you do not have a stomach, certain foods will be poorly digested ... I recommend splitting meals and repeated fluids." (HP_03)
"Patients want to know, above all, if they will be able to eat as before." (HP_05)		
2. Perceptive realignment	<i>Back to feeding by trial and errors</i>	"Haste is no longer possible." (P_01)
		"The ravioli ... I do not eat 30 like I used to, but 7-8 I do." (P_03)
		"There are days when I struggle ... days that I just cannot eat like I used to." (P_04)
		"I was afraid of getting the wrong thing to eat, afraid of the reaction it might give me." (P_06)
		"I eat almost everything ... everything ... I am just afraid. I eat 3-4 times a day ... that is how my life is. Life has changed me 360 degrees." (P_11)
	<i>Weight as a measure of well-being</i>	"I do not get fat though ..." (P_01)
		"The concept of weight is definitely something very important, but I do not focus on how much I weigh, let us say." (HP_01)
		"Weight is significant, it worries the patient the most, but it is not fundamental, there are other priorities. I tell patients to weigh themselves at most once a week." (HP_03)
"Weight represents an important clinical data even in clinical trials it is always required, so it is an important parameter for us." (HP_04)		
3. Rearranging food intake	<i>Reorganizing times, modes, and foodstuffs</i>	"If I do not sleep at night, I can get up and eat a brioche ... because I feel I am hungry. Now it is okay, let us say ... eating I eat a lot, more than my husband." (P_01)
		"I noticed that eating now ... I have to like it. I did not change my diet, but the times ... before I ate quickly, now I eat slowly." (P_03)
		"In the evening, I have dinner in steps ... I eat and then I have to stop because I have to drink ... after 15-20 minutes I start again with a piece of fruit maybe." (P_04)
		"I am happy with the way I eat ... I eat a little bit of everything." (P_05)
		"I still cannot get a normal meal! I always stick to certain times ... it is something I have to do. I also feed myself 5-6 times a day." (P_09)
	<i>Coming to terms with the lost food</i>	"I avoid schnitzel ... I have reduced portions and eat more often. I cannot eat meat anymore." (P_02)
		"Now I eat well-cooked foods, avoid alcohol ... I eat when I feel hungry, not at fixed times." (P_07)
		"Eating is a daily commitment." (P_10)
4. Food-regulated social interaction	"Always try to avoid going out to eat." (CG_01)	
	"Dinner with friends ... I do not go anymore!" (P_02)	
	"If I am with friends, I eat a little more." (P_03)	
	"Between one chat and another, I can eat more, having more time at my disposal." (P_04)	
	"If I have to go to a restaurant, I am afraid." (P_11)	

of self-induced discomfort through poor food choices. This led to difficulties regarding “what” to eat.

In addition to the fear of physical discomfort, this phase also emerged the fear of neoplastic cancer, particularly of a possible recurrence related to food choices.

In this phase, CGs and HPs maintained a role of reassurance in repeating the information given so that attempts/errors would not discourage the GCPs. Some patients expressed gratitude toward the CGs for their support and help. Others, however, complained of not feeling understood in their condition.

Weight as a measure of well-being

Given the weight loss following surgery, HPs (surgeons and oncologists) strongly recommended weight control. This became a “measure of well-being” for GCPs. Frequent reliance on the scale led to concern in some patients. Subsequently, physicians (oncologists and family doctors) adopted relational strategies to reassure patients. To avoid overuse of weight control, physicians recommended a maximum of once a week. In addition, they often reminded patients that a recovery of the original weight would not be possible and that the goal was weight stability, not weight gain.

Rearranging food intake

GCPs reported that it was only after numerous trial-and-error attempts that they increased their confidence in choice, resulting in a reduced fear of being sick. This situation allowed them to achieve a new, personalized diet. A perceived limiting characteristic of this unique dietary style was the inability to eat one or more of the foods regularly consumed before cancer. The conceptual categories informing this phase were: “reorganizing times, modes, and foodstuffs” and “coming to terms with the lost food.”

Reorganizing times, modes, and foodstuffs

The food reorganization involved eating all foods that did not cause discomfort, significantly reducing the fear and dread accompanying the early stages. GCPs said that they were satisfied with their reorganization even though it involved a very different timeline. The return to feeding involved the entire family and the whole day. Food became the factor around which GCPs’ and CGs’ daily schedules moved. The CGs said that they were committed to preparing food and feeling available for their loved ones’ food needs. During this phase, the physicians’ role consisted mainly of consolidating the patients’ choices, demonstrating a lack of specific preparation for the needs of these patients.

Coming to terms with the lost food

Most GCPs described at least 1 food they could no longer eat and stated sorry. GCPs regretted the specific food or habits they had before surgery. The sentiment that emerged was resignation; however, the willingness to find balance allowed them to overcome their limitations.

Food-regulated social interaction

Returning to eating involved both dietary reorganization and aspects of conviviality, which underwent significant changes compared to life before the intervention. Sharing meals with others became an issue to reflect on. Some interviewed GCPs happily resumed sharing meals with friends and family. In addition to the company of loved ones, an appreciation emerged for longer mealtimes to avoid physical discomfort. However, for other GCPs,

sharing meals led to the onset of discomfort, leading them to avoid such moments altogether. GCPs reported fear of feeling inadequate in public, preferring not to show others their dietary limitations. Some described concern about feeling judged or pitied. The role of CGs in this phase was diverse. CGs interviewed reported supporting their loved one’s choices. Some GCPs, however, described continuing to feel misunderstood even in this social dimension.

Discussion

The process of returning to eating after a total gastrectomy is intricate, involving GCPs, CGs, and HPs. The core category that our analysis developed is “defining a balance by compromising with fear.” GCPs experience significant eating-related fear, stemming from concerns about illness and tumor relapse. This process can be broken down into four key phases:

- Relying on the doctors’ advice. Initially, GCPs relied on the advice of HPs, finding their guidance helpful. However, this support proved insufficient over time.
- Perceptive realignment. GCPs began to listen to their bodies, engaging in a trial-and-error approach to regain their eating ability. Weight became a critical metric for assessing well-being despite efforts from HPs and CGs to contextualize it.
- Rearranging food intake. Achieving a sense of balance involved reevaluating the quality and quantity of food and how it was consumed. GCPs had to come to terms with the foods they used to enjoy.
- Food-regulated social interaction. Returning to eating had a profound impact on social interactions. The balance found by GCPs affected their ability to participate in social gatherings, and they had to contend with physiological limitations and feelings of shame.

Those existential features demonstrate to what extent patients and their CGs were left alone in their survivorship concerning feeding and nutrition. However, they also specify essential information for HPs and health-care providers to help patients-families to move forward.

Indeed, taken together, this study’s finding reinforces the urgency of designing care pathways (Allum et al. 2018; Bencivenga et al. 2018), managed by a multidisciplinary team (Bergin et al. 2020; Boniface et al. 2016), operating within a survivorship care plan (Antonowicz et al. 2020; Chhetri et al. 2020; LaGrandeur et al. 2018; Recklitis and Syrjala 2017; Soulia et al. 2019). Clinicians working with an extended group of allied professionals are vital for preventing GCPs and CGs’ unmet needs and supporting their transition to life after cancer treatment.

As to information our participants perceived as unsatisfactory, rehabilitation programs (D’Ugo et al. 2020; Engel et al. 2022) and individualized nutritional support (Mortensen et al. 2014) together may enrich the information oncologists and family doctors may give to GCPs and CGs for facing treatment sequela (Sundbom et al. 2020). Contextually, all the HPs should be trained on the first level of nutritional counseling within the care pathway by focusing on what matters to GCPs and CGs (Holdoway et al. 2022) after surgery.

The second phase, the perceptive realignment, entails a transformed proprioception that pushed participants to a trial-and-error modality of returning to eating. As Carrillo and Santamaría (2019) highlighted, GCPs experience a “strange body” that reacts strangely to food intake. Then, the only measure of well-being our participants could rely on was weight, an aspect that HPs and CGs

tended to relativize. Several studies show that “change in body weight” does not significantly affect postoperative QoL in gastrectomy patients (Kimura et al. 2021; Min et al. 2021). However, our results showed that psychological distress related to this issue was felt, exacerbated by feeling unwell in trying to eat. Correspondingly, professionals of the multidisciplinary care pathway could work on both needs. On the one hand, psychologists should detect distress early and appropriately treat it through different psychological interventions according to distress characteristics and components (Cao et al. 2019; Kim et al. 2017; Rupp and Stengel 2021). On the other, clinicians should follow internationally recognized dietary recommendations to counteract postsurgical symptoms, like diarrhea, nausea, vomiting, and early satiety (Rogers 2011).

The nutritional issue, however, would continue after having solved the biomedical and psychological problems. Most GCPs described at least 1 food they could no longer eat and said they regretted it, even though a compromise (with a feeling of resignation) was reached. Suppose gastrectomy took away the pleasure of food, forcing a change in habits, in that case, it need not also eliminate the pleasure of conviviality, especially in those cultures where the sense of social belonging conveyed by food and being together at the table is vital. The impact of cancer on nutrition is not only limited to nutrition and weight loss but also affects the social and cultural value of food (Cipriano-Crespo et al. 2021a). The symbolic and social values accompanying the traditional way of eating changed with gastric resection, worsening QoL beyond malnutrition (Carey et al. 2013; Carrillo and Santamaría 2019; Ellis et al. 2013; Rowsell et al. 2022). In other terms, QoL measures relate to the significance of eating in culture and social organization. More attention should be given to these cultural dynamics in clinical practice: our results suggest that a survivorship care plan should also consider anthropological and social aspects of eating (conviviality), not only psychological and nutritional ones.

Besides, another issue important for GCPs after gastrectomy and risking being overlooked by guidelines is social support for GCPs and their CGs. The balance reached by our participants does not include the desired social interaction since physiological limits (gastrointestinal problems, dietary restrictions, and excretory disorders) and shame strongly regulated GCPs' and CGs' conviviality, as mentioned elsewhere (Carrillo and Santamaría 2019; Cipriano-Crespo et al. 2021a, 2021b). Furthermore, the symptomatology and nutritional restrictions may trigger a loss of interest in meeting with family members and friends, according to Taleghani et al. (2021).

Even long after treatment, social functioning is crucial for an acceptable QoL (Recklitis and Syrjala 2017). Again, a multi-professional approach to GCPs' survivorship management could support them and their CGs in improving social participation (Choi et al. 2022; Paltrinieri et al. 2022a; Soulia et al. 2019; Zamanzadeh et al. 2018), including, if applicable, return to work (Paltrinieri et al. 2018, 2022b). Generally, fostering stable support during the cancer treatment and survivorship trajectory and creating a triadic relationship between survivors, CGs, and HPs (Bickford et al. 2018) are desirable.

Finally, the constant fear of cancer recurrence, which all our participants reported, is, unfortunately, one of the most frequent unmet psychological needs (Shin et al. 2022) and confirms the importance of psychological support within a multidisciplinary approach as well as of organizing survivor support groups by also involving their CGs as the primary support network (Carrillo and Santamaría 2019).

By conceptualizing the psychosocial process of returning to eating, as influenced by the perspectives of GCPs, HPs, and CGs,

we provided a framework for improving the quality-of-care pathways. HPs do not always consider those aspects, such as feeding, which significantly impact the patient's QoL and involve cultural and psychosocial factors. This is particularly true in Italy and other countries with an essential culinary tradition and a food culture firmly rooted in the population. Here, the difficulty in eating may determine a much more heartfelt change in the life habits of the GCPs and their CGs, because it alters personal relationships, drawing negative experiences related to food.

In light of our findings, we recommend an interdisciplinary approach to post-total gastrectomy patient care. It is crucial for health-care providers to acknowledge the psychosocial aspects of nutrition and involve nutritionists, psychologists, medical anthropologists, and other specialists early in the care process. Multiple actors can meet the nutritional, care, and psychosocial needs of GCPs and their CGs. However, the objective of establishing an interdisciplinary approach may not be immediately achievable in every oncological centers. Consequently, a set of practical recommendations that can benefit GCPs, CGs, and HPs may be suggested:

- Information material – providing GCPs with informative material during diagnosis, particularly focused on the initial phases following surgery. This material should offer simple yet valuable advice on nutrition, helping patients make informed choices.
- Nutritional training – offering basic nutritional courses and periodic refresher courses for HPs, including surgeons, oncologists, and general practitioners. This education may ensure that HPs are well-equipped to guide patients effectively (Caccialanza et al. 2020; Muscaritoli et al. 2021).
- Supportive platforms – establishing listening points or discussion groups for GCPs after surgery and CGs. These platforms can serve as spaces for patients to share their experiences, seek guidance, or ask questions of specialists. This peer support can be highly valuable in the recovery process.

By implementing these practical steps, we can make meaningful strides in improving patient care and support for those who have undergone total gastrectomy.

Strengths, impact, and research relaunches

To the best of our knowledge, this is the first study to describe a multi-stakeholder analysis of returning to eating and feeding after a gastrectomy. Among the strengths of this study, we may include the rigor of the methodological approach, which allowed us to gather rich interview data. The study population involves different key informants with diversified roles and responsibilities in caring for GCPs; nurses were excluded due to their limited role within the studied setting. This does not mean that nurses are less critical in the process (nurse-led follow-up has a similar impact on QoL than physician-led follow-up (Verschuur et al. 2009), with CGs being more satisfied with the former). An expanded GT study including nurses is a future research relaunch.

After this study's conclusion in our center, a nutritional assessment was provided for all GCPs (since surgery), and a new study could be proposed in the future. Also prompted by this study, nutritional support started for GCPs assisted as of 2018/2019 and became part of a postoperative surgical protocol during data collection. Besides, exploring the emotional, intimate, and social aspects experienced by GCPs after years could be a research advance for our center.

Researchers' reflections on the research experience

Participating in a qualitative research, particularly a GT study, necessitates a deep dive into the lives of individuals, enabling an in-depth exploration of their experiences as they navigate the challenges of illness and therapy. Given that several authors embarked on their first research endeavor with this study, incorporating a brief personal reflection paragraph becomes particularly significant. Reflecting on our individual journeys in this research provided insights into the personal growth and development that occurred during the study.

Qualitative research is distinctive in its focus on gathering and analyzing deep, personal, and emotionally rich data. It delves into phenomena that emerge during the research process, providing insights into the processes that are uniquely known to the participants. Consequently, we think that this method can reveal the most authentic aspects of illness – namely, the personal experiences of the individuals affected – rather than relying on assumptions made by HPs or researchers about illness and treatment responses.

The study undertaken allowed for an appreciation of the generosity and openness of the participants. These individuals were willing to share intimate and personal aspects of their lives, for which we express heartfelt gratitude. Above all, the research experience underscores the extraordinary value of the relationships, trust, and openness cultivated during encounters with patients and their families.

We also positively valued the experience shared with the research team. We consider it a precious reevaluation of our professional education, highlighting its significance on both a human and scientific level.

Limitations

The research setting was a cancer research hospital in a Western country. On the one hand, key informants in different locations may vary and engage in caring processes dissimilar to what we have conceptualized. On the other hand, as to the cultural sensitivity of GT studies (Morse 2001), our findings mainly apply to similar cultural contexts (predictably southern Europe).

Regarding methodological limitations, although we contacted the entire population of patients meeting the inclusion criteria, the number of cases was small. Nonetheless, a GT is modifiable by definition (Charmaz 2014; Glaser et al. 1968). Therefore, conducting an analogous study in other centers involving more patients, CGs, and HPs to verify whether our model can be extended to other GCPs' settings is desirable.

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