Articulating care and responsibility in design: A study on the reasoning processes guiding health innovators’ ‘care-making’ practices

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Highlights:
- Ethic of care and RRI are applied to examine health innovation design
- Designers direct their attention to unmet needs and ways to improve care
- They mobilise their skill set and seize opportunities to take care of problems
- As ‘care-makers,’ they prioritise key material qualities
- They are responsive to how care is received through user-centered practices
Abstract

This article explores how health innovation designers articulate care and responsibility when designing new health technologies. Towards this end, we draw on Tronto’s ethic of care framework and Responsible Research and Innovation (RRI) scholarship to analyse interviews with Canadian health innovators (n=31). Our findings clarify how respondents: 1) direct their attention to needs and ways to improve care; 2) mobilise their skill set to take care of problems; 3) engage in what we call ‘care-making’ practices by prioritising key material qualities; and 4) operationalise responsiveness to caregivers and care-receivers through user-centred design. We discuss the inclusion of health innovation designers within the care relationship as ‘care-makers’ as well as the tensions underlying their ways of caring and their conflicting responsibilities.
As “a practical matter of techne” (Groves, 2015: p 328), care is often enacted through technologies, including medical devices, information and communication systems, and care-dispensing tools. Yet, research on how those who design new health technologies think about care and translate this concept into their work remains scarce (Hendriks, Huybrechts, Slegers, & Wilkinson, 2018; Lehoux, Daudelin, Hivon, Miller, & Denis, 2014; Timmermans & Berg, 2003). Though the field of healthcare design can draw from robust scholarships on social responsibility (Cooper, 2019), empathy (Heylighen & Dong, 2019; Stacey & Tether, 2015), inclusivity (Luck, 2018), and participatory design (Østergaard, Simonsen, & Karasti, 2018), the work of health innovation designers is often excluded from the scholarship on caregiving and care-receiving. The latter rarely collects data upstream of the clinic, that is, before health technologies enter care practices (Buse, Martin, & Nettleton, 2018; Heath, Luff, & Svensson, 2003; Petrakaki, Waring, & Barber, 2014; Trondsen, Tjora, Broom, & Scambler, 2018; Turrini, 2011; van Hout, Pols, & Willems, 2015). While this scholarship may examine how designers’ intentions get embedded in technologies and influence their use (Pols & Willems, 2011), it rarely seeks to generate a better understanding of the reasoning processes guiding their design practices. Considering that designers employ a unique set of skills when developing new products and that artefacts “are not just the conduits for care” but part of how care relationships are constituted (Brownlie & Spandler, 2018: p 256), this gap warrants further exploration.

To pursue efforts to “rethink and reframe” technology and care (Mol, Moser, & Pols, 2010: p 15), we conducted a secondary analysis of qualitative data originally collected for a broader study in order to explore how health innovation designers reason around issues of care and articulate their responsibility to care when designing and bringing to market new health technologies (Neven, 2010; Pols & Willems, 2011; Timmons, Vezyridis, & Sahota, 2019). Towards this end, we draw from Tronto’s (1993) ethic of care framework and the Responsible Research and Innovation (RRI) scholarship because both integrate concepts central to the understanding of care and responsibility. While their focus differ, they share a similar overarching goal that resonates with growing concerns in design studies: to transform the ways in which we collectively define individual and societal needs and guide institutions and their actors in creating and deploying tools, services, and policies to meet these needs in a more equitable and sustainable manner (Owen, Macnaghten, & Stilgoe, 2012; Tronto, 1993, 2013).
We first summarise the premises of Tronto’s (1993) ethic of care framework and RRI and how a careful integration of their analytical strengths can shed light on “how care for others arises within the process of innovation” (Pavie, 2014: p 32). We then describe our qualitative study, which relied on interviews with Canadian engineers, industrial designers, entrepreneurs, and clinicians active in health innovation development (n=31). Our findings bring to the fore how respondents: 1) direct their attention to needs and ways to improve care; 2) mobilise their skill set to take care of problems; 3) engage in what we call ‘care-making’ practices by prioritising key material qualities; and 4) operationalise responsiveness to caregivers and care-receivers through user-centred design practices. Finally, we discuss the inclusion of health innovation designers within the care relationship as ‘care-makers,’ i.e., professionals who materialise care-dispensing tools, and the tensions underlying their ways of caring and their conflicting responsibilities.

1. Joan Tronto’s ethic of care framework and the ethics of care literature

In the 1990s, Joan Tronto laid the foundation for a feminist and political theory of care centred on interdependence (Hankivsky, 2014). Building on previous work with Berenice Fisher, Tronto (1993: p 103) defined care as “a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment.” Positioning care as a practice and a disposition, her ethic of care framework is comprised of four interconnected phases of caring (Tronto, 1993). They rely on four ethical elements of care underscored below:

1. Caring about relates to the awareness that a need exists and should be met, and it is supported by attentiveness;
2. Taking care entails the recognition that one can do something to address the unmet need and it involves assuming responsibility for care;
3. Caregiving refers to the direct meeting of care needs and it requires competence;
4. Care-receiving focuses our attention on care-receivers’ response to the care received to indicate whether caring needs have been met or not, thereby bringing responsiveness to the care process (Tronto, 1993).
Following her pioneering work, ethics of care scholars from a variety of disciplines have explored different conceptualisations of care ethics (Hankivsky, 2014; Laugier, 2015; Leget, van Nistelrooij, & Visse, 2019; Vosman, Timmerman, & Baart, 2018), including practice-oriented concepts of care (Martin, Myers, & Viseu, 2015; Mol et al., 2010; Puig de la Bellacasa, 2011) as well as the social, political, and economical contexts that condition care practices. For instance, feminist scholars have explored the asymmetrical power dynamics within social and political structures that shape interdependencies, including racism, colonialism, and capitalism (Murphy, 2015). Such interdependencies condition one’s “access to authority and resources” and how care may be delivered and received (Hankivsky, 2014: p 260). In this way, care is thus “a selective mode of attention” that “circumscribes and cherishes some things” and “excludes others” (Martin et al., 2015: p 627). Similarly, design scholars have argued that underlying values regarding what a good life entails point to the “problems designers choose to solve” (Chan, 2018: p 184). In other words, one should recognise that the design of care-dispensing tools is “not politically neutral” (Lloyd, 2019: p 176).

While Tronto’s (1993: p 103) definition of care easily resonates with engineering and industrial design by emphasising verbs such as “to maintain” and “to repair” (Pantazidou & Nair, 1999), a closer exploration of the connections between her ethic of care framework and RRI is warranted because it does not specifically address the social, political, and organisational dynamics that place technological innovation at the centre of care and which influence the scope of designers’ role in society (Cooper, 2019).

2. Innovation design through the lens of Responsible Research and Innovation (RRI)

The RRI scholarship stems from a European science policy context (Macnaghten, Owen, Stilgoe, Wynne, Azevedo, De Campos et al., 2014) and seeks to foster the design of innovations that are socially, economically, and environmentally more responsible. For Stilgoe, Owen, and Macnaghten (2013: p 1570), responsible innovation means “taking care of the future through collective stewardship of science and innovation in the present.” Key RRI principles include addressing societal challenges by engaging stakeholders in innovation development, anticipating potential problems, reflecting on the values and assumptions that underlie innovations, and
remaining responsive to emerging issues and shifting contexts (Macnaghten et al., 2014; Owen et al., 2012; Stahl, McBride, Wakunuma, & Flick, 2014). RRI thus aligns with current design research that aims to “understand the future,” to leverage creative design processes to solve global challenges, and to influence “policy by addressing upstream problems” (Cooper, 2019: p 14) as we enter the age of the Anthropocene (Chan, 2018).

RRI has established productive linkages with the work of Tronto (1993). For instance, reflecting on how RRI can guide society in taking care of the future, Groves (2009: p 1) argues that debates over the “intrinsically unknowable” risks of innovations for future generations should be informed by feminist concepts of care because they foreground a relational rather than an individualistic understanding of humans. In the field of management, Pavie (2014: p 21) draws from RRI and the work of Tronto (1993) to develop the concept of “innovation-care,” which emphasises how caring for the community and taking care of others should be prerequisites for innovating and doing business responsibly. Within a similar train of thought, André and Pache (2016) observe that caring is not the primary goal of for-profit enterprises, but suggest that care is pursued by social entrepreneurs who wish to maintain and repair their worlds. For Riley, Pawley, Tucker, and Catalano (2009: p 27), Tronto’s (1993) ethic of care is a relevant framework to understand engineering as long as the design process remains open to critique by the “cared for.” They also question whether engineers’ practices, market forces, and organisational hierarchies can be restructured around “real attentiveness to others’ needs” (Riley et al., 2009: p 30).

The extent to which designers’ practices are shaped by the organisational contexts in which they think and operate is one area that has been poorly addressed by the RRI community (Lubberink, Blok, van Ophem, & Omta, 2017). In healthcare, the design process unfolds in a context pervaded with both corporate and public service values that make the “concurrent pursuit of health and wealth” ambiguous and problematic for health innovation designers (Lehoux et al., 2014: p 750). Pointing out the market logics that condition innovation in precision medicine and the way “only certain futures are cared for,” Kerr, Hill, and Till (2018: p 28) stress that RRI is not equipped to account for commercial dynamics that have implications for social justice and equity. Yet, for Silva, Lehoux, Miller, and Denis (2018), the responsibility of the for-profit and non-for-profit organisations that design, develop, and bring to market innovations must be made explicit. The
extent to which designers can develop responsible products is conditioned by the organisation in which designers evolve, a point that resonates well with the design ethics scholarship (Lloyd, 2019).

In sum, Tronto’s (1993) ethic of care framework and RRI are not without limitations but offer relevant points of entry to examine the reasoning processes guiding the practices of health innovation designers. Because these bodies of knowledge provide concepts central to the understanding of care and responsibility, they are particularly well-suited to structure the current study, which aims to empirically explore how health innovators reason around issues of care and how they articulate their responsibility to care when designing new health technologies.

3. Methods

The objective of our broader qualitative study was to examine health innovation designers’ perspectives on what is responsible innovation in health and what it is not. Towards this end, we conducted semi-structured interviews guided by the Responsible Innovation in Health (RIH) value domains of Silva et al. (2018) and key findings were published (anonymised). RIH builds on key RRI principles while incorporating dimensions specific to healthcare such as health equity, health relevance, and health system sustainability.

3.1. Recruitment

Our purposeful sampling strategy aimed for internal diversification (Miles, Huberman, & Saldana, 2014). Those who design and develop health innovations typically work in teams and possess formal training in biomedical engineering, industrial design, or clinical sciences (Lehoux et al., 2014). In addition, designers who create a small or medium-size enterprise (SME) to bring to market a new product often add formal training in business to their initial skill set. We recruited participants from the two Canadian provinces that are the most active in the medical devices industry: Quebec and Ontario. We aimed for a roughly equal representation of genders, professional backgrounds, and provinces.
We conducted an extensive online search of both for-profit and non-profit organisations (e.g. universities, academic health centres, industrial design firms, etc.) to find potential participants who then received a personalised email and were invited to forward the solicitation to colleagues. To increase diversity, we also advertised our call through alumni associations, chambers of commerce, professional associations, incubators, and technology transfer offices. A total of 31 health innovation designers were recruited and most wore multiple professional hats (Table 1). For instance, an industrial designer by training could be an entrepreneur selling innovative products, or an engineer by training could hold a faculty position in a university research setting where innovation development took place. Respondents’ organisations where mainly split across non-profit research facilities (n=12), start-ups and incubators (n=12), and commercial enterprises (n=4).

The university’s health research ethics review board approved this study and respondents provided written informed consent prior to their interview.

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<td>• Medical device (e.g. monitoring devices, surgical devices, emergency care devices, frugal innovations)</td>
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<td>• Digital solutions (e.g. apps, telehealth, virtual reality, online platforms for mental health or home care services)</td>
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<td>• Other (e.g., health products, lab work, etc.)</td>
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3.2. Data collection

The first author conducted the semi-structured interviews over the phone or in-person. They lasted between 30 and 60 minutes, were audio-recorded, and transcribed verbatim. Prior to the interview, respondents visited a website where our team provided a brief description of RIH and of nine innovations illustrating different RIH attributes (e.g. health equity, frugality, eco-responsibility, alternative business models) (Copeland & Agosto, 2012). The interview questionnaire explored respondents’ design principles that guide their work, examples of innovations (from the website and their own), and how they perceive RIH.

3.3. Data analysis

The dataset was iteratively coded and analysed using the online software Dedoose™. For the purpose of this paper, we applied a thematic analysis strategy guided by Tronto’s (1993) ethic of care framework and by RRI’s approach to innovators’ responsibility. We drew from Tronto’s four phases and ethical elements of care to develop four descriptive questions through which we probed the empirical material (Figure 1). Because health innovation designers do not provide care, we adapted Tronto’s third phase, caregiving, to ‘care-making.’ This analytical adaptation offered a particularly strong fit with our data since it aptly conveys the pragmatic nature of designers’ work while remaining conceptually consistent with Tronto’s framework and RRI.
To iteratively develop and refine the thematic results indicated in Figure 1, we performed a thematic content analysis and created code-ordered matrixes to compare and contrast interviewees’ responses (Miles & Huberman, 1994). Our aim was to develop themes and sub-themes that captured the whole spectrum of variations in respondents’ views around the four descriptive questions. Because it entailed a secondary analysis of a dataset gathered for a broader study, we were careful not to conflate responsibility with care. We paid attention to how respondents described the design principles that matter to them and the examples they found particularly telling, either because of the responsibility they exemplified or lacked. We found that both care and responsibility are practice-oriented notions, but their scope differs. While the former is associated to what respondents may believe in, may be passionate about, and may seek to accomplish, the latter includes broader considerations about the organisations and institutions influencing their work. In other words, care evokes what one feels responsible for whereas responsibility refers to
what should be done and how in a given organisational context (see similar distinctions about designers’ responsibilities in Chan (2018)).

In the next section, the four themes introduced in Figure 1 are presented and illustrated with participant quotes (translated from French to English when applicable). Since the level of detail disclosed could entail a breach in confidentiality, we sent a preliminary version of our findings to respondents whose innovations were being described and obtained their approval.

4. Findings

We successively clarify the four thematic findings as well as the sub-themes upon which they rely. Readers can find a summary of these findings in Table 2.

Table 2. Summary of what designers care about and how they articulate their responsibility to care when designing health innovations

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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| Directing one’s attention to needs and ways to improve care | • Personal experience of a need  
  • Need shared by a segment of the population  
  • Need to improve current treatments and procedures for better patient care  
  • Tackling health inequalities |
| Mobilising one’s skill set to take care of problems | • Deploying one’s skill set to develop a product  
  • Being motivated to help others  
  • Identifying and seizing market opportunities |
| ‘Making care’ by prioritising key material qualities | • Ingenuity and usability  
  • Outperforming current solutions  
  • Impact for end users  
  • Raising the bar for the industry |
| Operationalising responsiveness through user-centred design | • Gathering users’ needs  
  • Integrating users into the design process  
  • Developing feedback mechanisms to improve capacity to meet users’ needs |

4.1. Caring about and attentiveness: Directing one’s attention to needs and ways to improve care

Respondents directed their attention to needs and ways to improve care in several ways. Their disposition to care about was associated to the personal experience of a need as well as to
attentiveness to unmet needs, to inadequate treatments and procedures, and to global health inequalities (see Table 2).

For at least three of our respondents, the decision to develop a new product was prompted by personal experiences as care-receivers. They created a small enterprise to make their solution available to others experiencing the same need. For example, a respondent “was confronted with the challenges” of using a medical device after being diagnosed with a chronic illness. As she looked for solutions and did not find any, she also realised how many others were struggling with the same issue: “I realised how huge this market is! […] And when I saw that, I decided that I was going to develop one” [P18]. She further explained how the values of her small enterprise were a driving force behind the development of her solution for this market:

The values of [name of company] are simple, they are to reinvent wellbeing. There are design solutions that are within reach and that can improve the quality of life of people. Often, there is a gap [in the market], either because nobody invested the time or bothered to do so. […] I want to make sure that there are individuals that will benefit from the end product. [P18]

Another respondent developed a new solution because of her frustrations with using a conventional breastfeeding pump. She radically changed this product and came up with an entirely new design:

When I developed my breastfeeding product, I was breastfeeding myself […] so I had a lot of knowledge, a lot of lived experience of what it is that women like me might need and appreciate in a product. I think that having a designer that has very good knowledge of the problem that the designer is addressing is [an] important aspect of how to achieve a good design. [P21]

Respondents cared about unmet needs shared by segments of the population, particularly vulnerable groups, as older adults and individuals living with a disability were described as not “getting the attention they deserve” [P23]. For instance, an engineer researcher who develops solutions for the ageing population stressed the importance of targeting “common problems that affect a lot of people,” such as preventing falls [P14]. Because with “any medical device, with good intents comes potential for harm” [P15], respondents stressed the importance of being attentive to safety issues and ways to reduce existing risks of injury by considering human factors and by “designing with purpose” [P15]. For example, an innovation that significantly reduces risks for
children suffering from severe food allergies [P30] as well as one that helps individuals who are in a wheelchair to navigate difficult spaces were considered responsible since “you’re preventing secondary problems” [P29].

As one of the “first criterion” for designing responsibly is obtaining the “evidence that the technology does as claimed” [P27], respondents cared about improving current treatments or procedures. The many examples discussed included an advanced technological platform that helps to improve the materials used in medical devices [P8], a gamification component created to better support patient rehabilitation [P16], and a digital platform to increase access to evidence-based mental health services [P25]. However, respondents were also critical of innovations that improved treatments or procedures without specifically attending to patients’ needs [P5]. A digital solution developer and entrepreneur explained the power imbalance that characterises decision-making in healthcare:

when you come up with something that reduces hospital costs, it will easily pass. When you come up with something that improves the doctor’s daily life, it will easily pass. If you develop a new drug or a new medical treatment, it will easily pass, but when you develop a solution that makes the patient’s life easier without directly addressing his cancer problem [for instance], no one wants to pay for it, nobody cares. Well, everybody says ‘ah that’s nice,’ but no one feels responsible for implementing or financing it. [P11]

Finally, some respondents explicitly cared about global health inequalities and stressed, for instance, the need for affordable low-tech diagnostic tools and imaging devices for low- and middle-income countries [P19, P31]. Because technologies are evolving so quickly and “manufacturers are not even bothering to keep low-end devices on their line-up,” these countries “are left with very few options” [P31]. Because “it’s not reasonable for us to implement something somewhere else that wouldn’t be acceptable here,” designing innovations that are “morally acceptable in all contexts” was seen as a more responsible practice [P13].

4.2. Taking care and responsibility: Mobilising one’s skill set to take care of problems

As underlined by an entrepreneur, every health innovator may believe to “have a responsible innovation in health” because he or she is “solving a health problem, saving lives, and making
things more efficient” but this is debatable [P23]. When discussing responsibility in further detail, our respondents made explicit their capacity to take care of health problems and assume responsibility for solving them by mobilising their professional skill set, helping others, and identifying, and seizing new product development opportunities (see Table 2).

Of the respondents who personally experienced a need, one took action by developing a “pretty strong advocacy” component to her product and was also looking to help a charitable organisation by providing “financial support for every purchase that people make” [P21]. Another explained how she chose to go into industrial design because she “wanted to make a difference in people’s lives” and assuming this responsibility was made possible by acting upon the values that “give birth to a product” [P18].

Taking care of problems also involved deploying innovators’ skills in the conduct of impactful product development and testing. After identifying the extent to which poorly designed winter boots put people at risk of injury, an engineer researcher mobilised his laboratories that “look like NASA” to test different brands and then shared the findings online to inform the general population:

I was really frustrated with how the number of falls is increasing and yet, people are doing lots of research into it. […] So I went out and bought some really expensive winter boots and tested them and found that they were really useless […] they were advertised to take you to the North Pole but if you stood on a 2° slope you’d slide off sideways. So I built a system to test winter boots and launched a website and rated 100 boots that were available to people and only 10 got one snowflake on my scale. So within two months there were over 2 million visits to the website and all of the boots that we said got one snowflake sold out. [P14]

Lastly, since one of the “driving principles” behind an innovation is a clear “value proposition that can deal with [an unmet need] better than anything else in the marketplace” [P26], our respondents took care of problems by identifying and acting upon market opportunities. When an industrial designer entrepreneur discovered that her product could respond to the needs of patients who suffer from a less prevalent yet more debilitating disease, she realised that she was “able to help them” as well since the product was already financed by her current client base [P18].
4.3. ‘Care-making’ and competence: ‘Making care’ by prioritising key material qualities

When discussing what innovators should do to make care-dispensing tools more responsible, our respondents underscored the importance of specific tangible qualities. The competencies underlying their ‘care-making’ role emphasised ingenuity and usability, outperforming current solutions, having a significant impact on end users, and raising the bar for the industry (see Table 2).

The ingenuity of different types of innovations was often described by respondents with a sense of awe, including, for instance, a low-cost device meant to protect nurses from needle-related injuries:

that little piece just had such an element of engineering and divine aspect to it that I was actually more blown away by that because there was so much thought that went into caring for the healthcare providers that I thought ‘wow!’ [P8]

‘Making care’ involved increasing the usability of innovations. An engineer entrepreneur’s team aimed to “make it easier for people to modify their behaviours” with an easy to use product that provides continuous feedback so “they don’t have to think back on it” [P12]. The idea of developing a new breastfeeding solution was motivated by the very low usability of conventional pumps: “they are very hard to clean, you have to take them apart and there’s a million little pieces and they all need to be cleaned and boiled separately” [P21]. In contrast, the respondent designed a device comprised of a single component that is easy to wash and can be repurposed.

The capacity to outperform currently available technologies was reported by respondents who discussed unsatisfactory treatment procedures and market dynamics that require constant product improvements. For instance, software platforms need to be updated and improved as technology advances, which “you have to do if you want be competitive and stay in the business” [P28].

Respondents highly valued innovations that have a tangible impact on end users. For instance, they shared examples of innovations that provided substantial improvements to the quality of life for those suffering from chronic diseases [P18], populations at risk of injury [P14, P30], and people with reduced mobility [P28, P29]. A respondent described an inspiring innovation she recently
came across – a home care solution that “doesn’t look like a medical device” and combines five separate devices into one portable device [P28]. She described it as life changing for both the patient and the caregiver:

Patients who are on life support at home […] need about five different pieces of equipment to go on their daily life […] and it makes portability very, very difficult. [For some], they want to go to university, to a movie, or to a restaurant […] but they’re limited because they have all this equipment and gears they’re dependent on. So what [name of the company] did is they [combined] five different devices into one [with] one power cord. […] it’s less intimidating for the caregiver, for the patient, […] So for the end user, it’s going to change their life for sure. [P28]

Last, in their role as ‘care makers,’ respondents underscored how design competencies can raise the bar in the health innovation sector. The five-in-one portable device described above was lauded for setting a new standard:

I think there’s about 400 patents in that device, and there is absolutely nothing on the market that can compete with it; and it’s just genius if you ask me. This is a company of engineers [who] poured in all their money and all their know-how and they came out with this device that is going to revolutionise healthcare in the chronic home ventilated patient population. [P28]

Following the media attention the winter boots initiative (described above) received, the shoe industry not only started making better boots but the research team also developed a new material to further improve the performance of the soles:

Senior members of the industry […] wanted to work with us […] and said, ‘we won’t buy for this next winter unless you test.’ […] we had the first prototypes for the next year coming in, and they are considerably better. So we have changed the buying habits, we have changed the industry, we ourselves have developed a new kind of boot material which we expect will be in production within two years, which is spectacular. [P14]

Through pilot studies, the engineer researcher indeed observed that their solution had cut the number of incidents by 4.75 times. Another entrepreneur active in the rapidly evolving digital health field underscored the need to increase standards for the digital health industry as a whole. She worried about the possibility that “a lot of companies who are not responsible
in the way that you guys are talking about it and in the way that I think about it, flood the market” and establish a low standard [P25]. Such a view was shared by a biochemist who worried about individuals for whom healthcare is “a three trillion-dollar market:” “those are the people that need responsible innovation frameworks” [P17].

4.4. Care-receiving and responsiveness: Operationalising responsiveness through user-centred design practices

Though health innovators are not involved in care delivery unless they hold a clinical background, their responsiveness to how care is received by patients is manifested through the user-centred design principles that guide their work throughout the innovation development lifecycle. That is, from the gathering of user needs at the onset of a project to the development of user feedback mechanisms once the product is on the market (see Table 2).

Prior to the development of a solution, respondents explained how they consult and interact with future end users with the intent to properly understand their desires, constraints, and context of use. For instance, an innovative paediatric care clinic “started with an actual need” identified by formal and informal caregivers for treating severe food allergies: “It’s a patient’s mother who said, ‘I know that you’re doing some research on this, and I’d like our [patient association] to help fund this clinic’” [P30].

During the innovation development process, working closely with “need knowers” such as caregivers and patients enabled respondents to develop responsive solutions [P16]. For a digital tool developer, one has to be “really, really careful” and not “come up with something out of thin air that could actually harm patients” [P25]. She stressed the importance of “brining in clinicians from a wide variety” of backgrounds as well “frontline workers” because their “insight is just much more relevant than” hers. Because some of the problems in healthcare “can be overwhelming,” a user-centred approach was described as an effective way “to explore a problem space in a very structured, more rigorous manner” [P22]. In addition, potential users “are interested in having a voice and being able to influence the product” and thus “collaborate a great deal” [P18].
Finally, when discussing whether an innovation successfully meets care-receivers’ needs, respondents pondered the economic incentives that distort how needs get to be fulfilled or not. If formal caregivers were “just given the luxury of more time” to spend with patients, a number of innovations may not be needed [P8] and innovations with “no strong evidence that they actually do anything for people” were easy to find [P27]. For an engineer researcher, about “one third of medical devices are completely inefficient” and “stay on the market” because of profit incentives [P10]. Considering that a product is unlikely to “fit everyone 100%,” the importance of integrating feedback loops within one’s business strategy was highlighted by an industrial designer entrepreneur:

> What we say to people is ‘buy it and if you don’t experience the benefits that you are supposed to, we will reimburse you. But we want to talk to you to understand why it didn’t work. Because the why it didn’t work is much more important to us.’ […] I also developed a small team of testers [and every time improvements are brought, they] give me feedback. [P18]

5. Discussion

Guided by Tronto’s (1993) ethic of care framework and RRI, our qualitative study focused on the ways in which health innovation designers reason around care and responsibility and translate these notions into their work. Our study’s contribution to current knowledge is two-fold.

5.1. Conceptualising health innovation designers within the care relationship as ‘care-makers’

First, because we examine the reasoning processes guiding a practice that is not typically seen as a place of care (Turrini, 2011), our study contributes to the literature on practice-oriented concepts of care (Martin et al., 2015; Mol et al., 2010; Puig de la Bellacasa, 2011) by foregrounding health innovation designers as ‘care-makers,’ that is, professionals whose daily work is to envision, design, and materialise care-dispensing tools for, and often with, care-receivers and caregivers. Our findings clarified what they aim to accomplish before care-dispensing tools make their way into care practices. Acknowledging that designers’ practices are neither entirely nor solely driven by care-oriented principles, our study showed how our respondents: directed their attention to needs and ways to improve care; mobilised their skill set to take care of problems; ‘made care’ by
prioritising key material qualities; and operationalised responsiveness to caregivers and care-receivers through user-centred design.

As such, our exploratory findings provide a novel empirical basis for scholars to: a) position health innovation designers within the care relationship alongside caregivers and care-receivers, thus opening up the typical dyadic vision of care (Tronto, 2013); and b) identify and further develop design skill sets for this role. The positioning of health innovation designers as ‘care-makers’ is aligned with a design practice that favours a cross-disciplinary and “inclusive landscape of design knowing and being” (Adams, Daly, Mann, & Dall’Alba, 2011: p 605). It also calls for design skills to think and work across different perspectives (Adams et al., 2011). More specifically, the action-oriented elements of Tronto’s (1993) framework suggest examining what scope of attentiveness to needs is relevant to health innovation designers’ practices, to what extent they should assume certain responsibilities and delegate others, the practical skills they need to mobilise, and the processes they should put in place to increase their responsiveness to how care is given and received. For instance, by conceptualising the work of health innovation designers as part of the care relationship (Brownlie & Spandler, 2018), they become not only responsible for the development and implementation of safe and effective health innovations (e.g., obtaining regulatory approval), but also for the quality of care delivered and received through the health innovation. By extending the focus of health innovation beyond safety and effectiveness to ‘care-making,’ health innovation designers become involved in the iterative implementation and refinement process with end users until concerned parties are satisfied with the quality of care enabled through the health innovation.

5.2. Tensions underlying designers’ ways of caring and their conflicting responsibilities

The second contribution of our study is to shed light on some of the tensions underlying designers’ ways of caring and the conflicting responsibilities that affect health innovation design, as these issues are far from fixed, settled, or easily solvable (Hendriks et al., 2018; Lloyd, 2019).

Pursuing the work of RRI scholars who argue for a more caring approach to responsible innovation (André & Pache, 2016; Groves, 2009; Kerr et al., 2018; Pavie, 2014), our findings underscore
how the multi-dimensional concept of responsibility (Macnaghten et al., 2014; Stahl et al., 2014; Stilgoe et al., 2013) can elucidate ways in which care is “a selective mode of attention” (Martin et al., 2015: p 627) in health innovation design. Because the relationships between the innovation development processes, the final product’s features, and the commercial orientation of the organisation that brings this product to market influence its degree of responsibility (Silva et al., 2018), these aspects must be considered altogether if one wishes to understand how designers’ ‘care-making’ efforts influence what kinds of needs are addressed and what types of care-receivers may or may not be cared for later on (Brownlie & Spandler, 2018; Groves, 2015). Whose needs are cared for and how are social justice and equity issues at the heart of feminist work on care (Murphy, 2015). While for some, taking care of others should be required to innovate responsibly (Pavie, 2014), by bringing care directly into innovation development processes rather than assuming it is the outcome of its use, our conceptualisation of health innovation design as a ‘care-making’ practice may offer RRI scholars a pragmatic lens to consider how commercial dynamics of innovation development impact social justice and equity (Kerr et al., 2018).

Though designers may be personally motivated by empathy and a sense of responsibility towards others (André & Pache, 2016; Heylighen & Dong, 2019; Kullman, 2016; Riley et al., 2009), hierarchical structures determine what they will or will not accomplish (Hankivsky, 2014) as they work in systems that are “inherited, and formed by” prior design initiatives and practices (Chan, 2018: p 195). Because health innovation design sits at the interface of healthcare institutions and the medical devices industry, responsibility in this context is “networked” across several actors and organisations (Timmermans, Yaghmaei, Stahl, & Brem, 2017: p 7). As such, in addition to professional codes of conduct and social responsibility principles (Chan, 2018; Cooper, 2019; Lloyd, 2019), health innovation designers must also contend with the different forms of responsibility that coexist in health systems and are in tension with one another (Kerr et al., 2018), as well as market constraints and opportunities (Riley et al., 2009). Indeed, while our respondents showed enthusiasm for devices they consider well designed as well as marketable, they also shared ambivalence towards unneeded innovations and underscored both the impact of their work and their limited room for error. Furthermore, they were critical about innovations that lack responsibility, what gets purchased in health systems, and how third-party payers do not feel
responsible for patient-oriented solutions. Consequently, scholars should recognise the highly institutionalised context in which certain health innovation designers operate.

Overall, as much as care cannot be understood “as a unitary, monolithic phenomenon” (Turrini, 2011: p 76), health innovation designers’ ‘care-making’ practices should be understood as multifaceted and subject to professional, institutional, and market influences.

5.3. Study limitations, further research, and concluding remarks

We recruited participants who were interested in responsible innovation and thus more likely to be reflexive about their practices. Because our study was not originally focused on care but on responsibility, our analyses could not aim for empirical saturation. By applying Tronto’s (1993) framework in a deductive manner, the likelihood of generating emergent thematic findings was limited. The transferability of our findings is limited to settings that are similar to those where our respondents were practising. They thus do not reflect practices in large companies that manufacture and distribute medical devices worldwide.

Further research on the conceptualisation of health innovation designers as ‘care-makers’ could examine what this role entails in their day-to-day practice. The tensions and systemic barriers and facilitators that our study pointed at deserve further in-depth investigation. Examining whether and how designers can address power dimensions based on gender, ethnicity (Lloyd, 2019), and market forces would be warranted (Murphy, 2015). Because “the process of becoming professionals is always open-ended and incomplete” (Adams et al., 2011: p 590), scholars could seek to provide a more comprehensive account of the impact of innovations “produced with and for care” (Puig de la Bellacasa, 2011: p 96) and guide designers in their practice when ‘making care.’

In conclusion, considering that care-dispensing tools are inseparable from what their designers care about and the way they articulate their multiple responsibilities, this paper suggests that health innovation designers are key actors in care practices, even if their role is not conceptualised as such.
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Declaration of competing interests

The authors declare that they have no competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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