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Innovative work behavior in healthcare: The benefit of operational guidelines in the treatment of rare diseases

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ABSTRACT

Objectives: Innovative work behavior is a core demand of healthcare professionals who treat patients with rare diseases. In healthcare services, determinants of innovative work behavior are not completely detected. This paper focuses on how the existence of guidelines and the flexibility of healthcare professionals in taking on extra roles in the workplace enable innovative work behavior.

Method: We used survey data from 160 healthcare professionals working in Germany in the field of rare diseases, including physicians, caregivers, and therapists. A mediation model was statistically tested using linear multiple regression analysis.

Results: The existence of guidelines for operational processes contributes to innovative work behavior by integrating the stages of knowledge acquisition, idea generation, and solution implementation. Individuals' flexibility in their role ownership mediates this relationship. In addition, we found evidence that physicians are more active in acquiring knowledge, whereas nurses or therapists show more initiative in generating new ideas.

Conclusion: Engaging in different roles enables healthcare professionals to demonstrate initiative for innovative work behavior aside from the completion of their daily tasks. The assumption of new roles may be encouraged by the creation of overall guidelines that raise awareness for the workers' need to take on extra tasks and innovative behavior.

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1. Introduction

Generating innovative solutions is imperative for healthcare services in the field of rare diseases. Following the European Union Orphan Drugs Regulation [1], a disease is defined as rare when it affects fewer than 5 out of 10,000 people. Such low prevalence results in a serious knowledge deficiency in the scientific, managerial, and operational service areas involved in treating such diseases. In the rare-disease care environment, it is essential to respond

E-mail addresses: maura.kessel@tu-berlin.de (M. Kessel), henrike.hannemann-weber@tu-berlin.de (H. Hannemann-Weber), jan.kratzer@tu-berlin.de (J. Kratzer). rapidly to developing demands and needs [2]. Physicians, therapists, and nurses must participate in adapting and modernizing standards and must apply novel techniques and procedures to ensure effective healthcare services [3]. Due to the lack of treatment options, the absence of specific guidelines, and problems in allocating responsibilities, innovative work behavior is required by all healthcare professionals involved in the care or treatment of patients with rare diseases. Innovative work behavior has been defined as employee-led initiation, and realization of new ideas within a work role designed to improve role performance [4–7]. Healthcare professionals' innovative work behavior may emerge in incremental adaptations of existing healthcare processes, services or products, or as entirely new practical solutions. We define innovative behavior as not only consisting of the initiation and realization of novel approaches but also of the accumulation of knowledge

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taking as a basis for the aforementioned activities. In the literature, various researchers claim that innovative work behavior is critical for the effective functioning of organizational systems in a variety of realms [4.5.8.9]. However, in the healthcare service field, innovative work behavior has not traditionally been a mandatory aspect of daily practice but rather something beyond the scope of healthcare professionals' prescribed work behavior [10,11]. In previous studies, various antecedents of innovative behavior have been detected, which often focus on informal governance mechanisms, such as norms and attitudes [e.g., 12,13]. In the field of healthcare, however, the existence of formal governance, particularly clinical guidelines, has a long tradition and characterizes routine work in both outpatient and inpatient settings. For most of the approximately 6000 distinct rare disease patterns, formal mechanisms, including comprehensive guidelines, are lacking [1]. Numerous institutions have established internal guidelines: nevertheless, the majority of healthcare professionals are left to provide care and treatment without protocols for good clinical practices.

In this paper, we address the challenge of uncertainty stemming from an absence of standardized protocols and responsibilities. We also investigate how the existence of guidelines affects flexibility within work roles and shapes innovative work behavior. In the last decade, researchers have become increasingly interested in combining insights from innovation management research and health services research [14–21] to underpin discussions on health policy issues. We contribute to this literature by identifying conditions that influence innovative work behavior among healthcare professionals and discuss initial policy implications.

2. Theoretical framework and hypotheses

The rewards of innovation include both better functioning of the healthcare organization itself and the achievement of adequate individualized solutions for each patient. However, the innovation process is complex and multifaceted which indicates an in-depth view on the sequenced stages. Active knowledge acquisition enables the creation of new solutions [22,23] by combining new and existing knowledge to generate new ideas [24]. It is of vital importance, particularly in uncertain and knowledge intense environments [25,26]. Knowledge, defined as "a fluid mix of framed experience, values, contextual information, and expert insights [...]" [27], represents the basis for evaluating and incorporating new information and generating new ideas [28,29]. When knowledge is processed, the range of potential behaviors is increased and, by definition, learning has occurred [30]. In learning and knowledge processing, novel and useful ideas can be generated in a second phase. The production, conceptualization, and development of new and improved ways are the essence of creativity [31]. Creativity differs from innovation in that creativity is the creation of new ideas by individual employees, whereas innovation also involves the successful implementation of ideas [32]. Thus, the last stage in the innovation process comprises the implementation of new solutions. Once an idea is generated, it can either be realized by the "creator" himself, and/or it can be promoted to colleagues to build an alliance that can bring the idea to fruition [4,33]. Through the implementation of new ideas, the innovative solution can be experienced and applied in daily working processes [34]. On the basis of the arguments above, we consider innovative work behavior to be multifaceted behavior consisting of a set of three tasks: knowledge acquisition, idea generation, and solution implementation.

Several studies suggest that organizations' structural properties influence employee outcomes in general and innovative performance in particular. According to Hage and Aiken [35], one of the central structural parameters in the context of health organizations is the formalization of operational procedures. They describe formalization as the utilization of work rules in an organization that specifies work tasks and the degree to which employees are guided in conforming to the task's codified standards. Burns and Stalker [36] stated that mechanistic structures are appropriate for organizations that operate in relatively certain or predictable environments, whereas organic approaches are required under uncertain and complex conditions. However, a meta-analysis by Damanpour [37] demonstrated inconsistent results from the formalization of innovative performance. On the one hand, flexibility and a low emphasis on work rules facilitate innovation [36,38]; on the other hand, a demand was found for well-established, clearly specified guidelines for successful innovation processes [39,40]. The latter results were underpinned by the results of Palmer and Dunford [41], which state that a greater use of new organizational practices, such as de-layering, empowerment or flexibility in work groups, is associated with an increased use of formalization. Due to the broad distribution of knowledge in the care and treatment of rare diseases, all involved healthcare professionals must display innovative work behavior. Such a goal may be attained by empowering employees lower in the hierarchy. Adler and Borys [42] distinguish between coercive and enabling formalization. The enabling type of formalization is experienced as a cooperative endeavor: it facilitates task performance and work flows. In healthcare services, evidence suggests that physicians' job satisfaction is enhanced by formalization [43] and that the emotional exhaustion of daycare employees decreases as additional structured programs are introduced [44,45]. Uncertainty is compounded by the healthcare service context, in which the outcome directly affects patients, resulting in even greater uncertainty. Innovative work behavior itself is associated with high uncertainty and depends on the employees' motivation. Such motivation may be easily inhibited by the aforementioned task uncertainty and resulting feelings, including stress or dissatisfaction. At this, the purchasing of guidelines is seen as (1) bringing order into the confusion of widespread variations - a reduction of uncertainty can be achieved, and (2) promoting the motivation for innovation by the prevention of negative feelings triggered by ambiguous working conditions. We believe that "enabling" mechanistic structures are necessary to overcome uncertainty, to assure standard operating procedures, and to facilitate initiatives for unpredictable, innovative actions – especially in the field of rare diseases, where guidelines for operational procedures are frequently lacking. Therefore, we hypothesize that the existence of guidelines for operational procedures in the rare disease work environment affects multi-faceted innovative work behavior.

Hypothesis 1. The existence of guidelines will be positively related to healthcare professionals' innovative work behavior.

Hypothesis 1a. The existence of guidelines will be positively related to healthcare professionals' knowledge acquisition.

Hypothesis 1b. The existence of guidelines will be positively related to healthcare professionals' idea generation.

Hypothesis 1c. The existence of guidelines will be positively related to healthcare professionals' solution implementation.

Beyond examining the relationship between operational guidelines and innovative work behavior, we also focused on exactly how operational guidelines influence healthcare professionals' innovative work behavior. Socialcognitive theory suggests that humans are self-regulating agents who are producers of their environment [46], suggesting that structural properties affect outcomes by affecting the employee's internal state [47]. To ensure adequate treatment of patients with rare diseases, it is of vital importance that healthcare professionals assume responsibilities beyond their core tasks of routine healthcare and propose innovative solutions. Healthcare professionals working in the field of rare diseases are expected to embody a broader and more proactive approach to their work role, as described by the concept of flexible role orientation developed by Parker et al. [48]. Here, the execution of additional work roles by employees to aid in achieving more than basic goals is of central interest. Several authors have proposed flexible role ownership as an important determinant of proactive work behavior [49–52]. Proactive behavior is defined as "taking the initiative in improving current circumstances" [53] via the acquisition of extra knowledge to solve problems, the generation of new solutions or the implementation of novel concepts to challenge the status quo. Underlining this idea, Howell and Bois [54] noted that flexible role orientation is positively related to idea generation. We argue that assuming flexible roles is action-oriented and therefore modifiable in response to environmental changes [48]. Thus, the existence of guidelines for operational procedures reduces the complexity and ambiguity in the care and treatment processes, in addition to decreasing role ambiguity [55]. Numerous studies have indicated that formalization reduces both role ambiguity and role conflicts, which may increase the feeling of stress and dissatisfaction [for a review, see, e.g., 56]. Only when work roles are clarified may employees shift professional roles or assume additional tasks. Formalized processes entail certainty and trust. Therefore, such processes support employee risk-taking behavior [56]. Healthcare professionals who are confident in their care and treatment processes are more likely to take risks in assuming wide-ranging roles and, as a consequence, to demonstrate innovative work behavior.

On the basis of the above arguments, we propose that the existence of guidelines for operational procedures in the rare-disease work environment affects the motivational state of flexible role ownership, which in turn leads to multi-faceted innovative work behavior.

Hypothesis 2. Healthcare professionals' flexibility in role ownership will mediate the relationship between the existence of guidelines and innovative work behavior.

Hypothesis 2a. Healthcare professionals' flexibility in role ownership will mediate the relationship between the existence of guidelines and knowledge acquisition.

Hypothesis 2b. Healthcare professionals' flexibility in role ownership will mediate the relationship between the existence of guidelines and idea generation.

Hypothesis 2c. Healthcare professionals' flexibility in role ownership will mediate the relationship between the existence of guidelines and solution implementation.

3. Methods and materials

The sample for the study questionnaire comprised 160 healthcare professionals who were actively involved in the operational care and treatment processes of patients with one of six pre-defined rare diseases in Germany. The disease patterns were selected by an expert committee based upon differences in prevalence and affected organs (selected diseases: Amyotrophic lateral sclerosis, Marfan's syndrome, Wilson's disease, Epidermolysis bullosa, Duchenne muscular dystrophy, and Neurodegeneration with brain iron accumulation). Healthcare professionals were identified through their working relationship with patients and were subsequently asked to fill out the survey. Participation was voluntary at each stage, and the survey cover letter guaranteed confidentiality. This recruitment approach assured the inclusion of a broad representation of healthcare professionals from diverse disciplines and hierarchical levels. Of the respondents, 57.5% were general practitioners or other physicians in hospitals and ambulatory settings, and 42.5% were therapists, nurses, and healthcare aides. In addition, 47.5% of the respondents were male, and 52.5% were female. The average age of the respondents was 46 years. The total response rate was 34%. The survey was designed primarily using previously validated scales. All variables highlighted individual activities and perceptions concerning the care and treatment processes of the specified rare disease (each questionnaire focused exclusively on one disease pattern indicated by the patient). Self-reporting was utilized, although this method has been criticized in the literature because humans are arguably incapable of accurately reporting their own performance due to poor introspection capabilities [57]. Nevertheless, the concepts regarding perceptions and activities can hardly be assessed objectively. Heneman [58] observed that selfreported measures are less limiting in range and leniency than objective ratings. We designed our instrument (see Appendix) by adapting existing operationalizations and measurements. For the item scales, we used 7-point Likert scales ranging from 1 (strongly disagree) to 7 (strongly agree) to the extent possible.

The existence of guidelines for operational procedures in the care and treatment of rare diseases was assessed with five items originally developed by Hage and Aiken [35]. These items have been used by many other studies. e.g., Gupta [59], and further developed by Dyer and Song [60]. These items loaded on a single factor with an eigenvalue of 3.75 with factor loadings ranging from .74 to .91. The reliability of this scale was α = .91. The extent to which healthcare professionals feel ownership for occupational problems beyond their immediate operational healthcare tasks was measured with items from the flexible role ownership scale developed by Parker et al. [48] and adapted to the given context. The scale comprised 9 items, but one was omitted due to poor factor loading. The remaining items loaded on a single factor with an eigenvalue of 4.80 with factor loadings from .57 to .87. The reliability was α = .90.

Innovative work behavior was defined according to the configuration of an activity set consisting of knowledge acquisition, idea generation, and solution implementation. Each stage of the innovative work behavior construct was measured and further analyzed separately. To examine knowledge acquisition activities, each respondent was asked to select the information sources he/she used from ten possible options. The number of indicated information sources was used as a proxy for the degree of knowledge acquisition concerning diagnoses, symptoms, therapies, the state of research, and healthcare procedures and processes. Idea generation was assessed using three items from a scale for creativity previously developed by Zhou and George [32]. We extracted these items because they represent the ideageneration stage in the process of innovative work behavior and are appropriate in the context of healthcare professionals working with rare diseases. These three items loaded on one factor with an eigenvalue of 2.72, with loadings ranging from .86 to .91 and a reliability of α = .92. To measure the final stage of innovative work behavior, characterized as solution implementation, individuals were asked to indicate how many new solutions they had devised in the last 24 months regarding treatment methods, care processes or curative means and aids. If they had at least one, they were asked whether they had implemented it themselves. The total number of the self-implemented ideas was used as a proxy for solution implementation.

Finally, we controlled for several aspects to limit the influence of unobserved variance. Therefore, we integrated disease *prevalence* such that the lower the prevalence of a disease, the higher the uncertainty due to limited available information. The prevalence was extracted from the Orphanet database (www.orphan.net) and was defined as the number of patients out of 100,000 affected by one specific rare disease. We also controlled for the *age* and *sex* of healthcare professionals and added the variable *expertise* along with dummy coding to indicate whether the respondent has a medical degree. A final control variable, *experience*, was indicated by the number of patients who suffer from a given rare disease and who have been treated by the healthcare worker.

We used a regression analysis to test the relationships between the predictor variable (the existence of guidelines for operational procedures) and the dependent variable (the healthcare professional innovative work behavior) along with the mediating effect of their flexible role ownership.

4. Results

We tested mediation hypotheses with multiple linear regression analysis. Following Baron and Kenny [61], a variable is considered to be a mediator when four conditions are met: (1) the independent variable should have a significant relationship to the outcome, (2) the independent variable should have a significant relationship to the mediator, (3) the mediator should have a significant relationship to the outcome, and (4) when the mediator is specified in the full model, the relationship between the independent variable and the outcome should become insignificant.

Table 1 presents descriptive statistics and correlations for all measures. Before conducting a regression analysis, we examined residual plots, collinearity diagnostics, and Durbin–Watson statistics to verify that regression assumptions were met. We first introduced a block of control variables into the equation, followed by the independent and mediating variables for each dimension of the dependent variable innovative work behavior separately (Table 2).

The second model of each dependent variable presents the results of the first regression and supports Hypotheses 1a-c and the first condition for mediation. We found a positive relationship between the existence of guidelines and knowledge acquisition (β = .30, p < .01), idea generation (β = .17, p < .05), and solution implementation (β = .20, p < .05). We next examined whether the independent variable contributes to the mediator (see the last column in Table 2). The results indicated a significant, positive relationship between the existence of guidelines and flexible role ownership (β = .26, p < .01). For that reason, the second condition for mediation was met. Moreover, the third condition for mediation was confirmed for all three dimensions of innovative work behavior [knowledge acquisition $(\beta = .25, p < .01)$, idea generation $(\beta = .29, p < .01)$, and solution implementation (β = .22, p < .01)]. The results proving the fourth condition of mediation varied between the three dimensions of innovative work behavior. As shown in the full model of knowledge acquisition, both of the coefficients of the supporting and the mediating variable remained significant (flexible role ownership β = .19, p < .01, existence of guidelines β = .23, p < .01). In line with Hypothesis 2c, the results indicate a meditating effect of flexible role ownership as well as a direct effect due to the existence of guidelines. In contrast, in the full model of idea generation and solution implementation when flexible role ownership is controlled, the coefficients for the existence of guidelines become non-significant (idea generation: β =.07, n.s.; solution implementation: β = .14, n.s.). Following Barron and Kenney [55], this finding supports Hypotheses 2a and 2b and indicates that flexible role ownership fully mediates the relationship between the existence of guidelines and idea generation and, accordingly, solution implementation.

Table 1Means, standard deviations and correlations.

Variable	Knowledge acquisition				Idea generation				Solutio	n impler	Flexible role ownership			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2
Prevalence	08	14	09	12	.04	03	.02	.01	.03	.01	.02	.01	.06	.04
Sex	.09	.07	.11	.10	14	17^{*}	11	11	.06	.06	.09	.08	10	10
Age	14	09	11	08	10	06	08	07	30^{**}	25^{**}	27 ^{**}	24^{**}	09	05
Expertise	.21**	.18*	.24**	.22**	20^{*}	23 ^{**}	17^{*}	18^{*}	12	12	10	12	11	13
Experience	.34**	.27**	.31**	.26**	.23**	.20*	.19*	.18*	.09	.09	.06	.03	.14	.07
Flexible role ownership			.25**	.19**			.29**	.27**			.22**	.19*		
Existence of guidelines		.30**		.23**		.17*		.07		.20*		.14		.26**
ΔR^2		.07	.06	.04		.04	.07	.01		.04	.05	.02		.04
ΔF		15.60**	11.46**	8.95**		4.26*	5.16*	.60		5.12*	7.41*	2.50^{*}		9.33**
R^2	.21	.28	.27	.31	.10	.14	.17	.18	.12	.16	.17	.19	.04	.10

N = 160.

* *p* < .05.

Table 2 Regression analysis results.

	Variable	Mean	s.d.	1	2	3	4	5	6	7	8	9	10
1.	Prevalence	9.89	12.90										
2.	Sex	.53	.50	21**									
3.	Age	46.29	9.50	.13	06								
4.	Expertise	.57	.50	.27**	34^{**}	.09							
5.	Experience	71.26	185.38	.12	03	12	.17*						
6.	Flexible role ownership	5.27	1.10	.03	05	11	08	.14					
7.	Existence of guidelines	3.39	1.78	.12	07	14	.12	.31**	.27**				
8.	Knowledge acquisition	4.73	1.81	05	00	14	.22**	.39**	.25**	.39**			
9.	Idea generation	4.66	1.60	07	07	12	17^{*}	.22**	.37**	.22**	.34**		
10.	Solution implementation	3.70	5.38	06	.12	33 ^{**}	18^{*}	.12	.30**	.23**	.24**	.36**	

N = 160.

5. Discussion

In this study, we were primarily interested in how healthcare professionals who work with patients suffering from rare diseases can be encouraged to produce more innovative work behavior. Such behavior is essential because routine solutions for these diseases do not exist due to a lack of research and practical guidelines. The results support the hypothesis that the degree of the existence of guidelines is significantly related to each dimension of innovative work behavior: acquiring knowledge, generating new ideas for adequate care concepts and implementing those ideas in the care process (Hypothesis 1). Although previous studies have noted that more organic structures enhance innovative performance [36,56], in uncertain contexts, such as the treatment of rare diseases, the existence of guidelines may ensure more safety, which in turn enables healthcare professionals to display innovative work behavior. Our findings also demonstrate that healthcare professionals who are willing to assume tasks outside of their prescribed or intended work role are more likely to demonstrate innovative work behavior. Such findings align with prior research demonstrating that individuals who are inclined to take on flexible work roles have a higher sense of personal responsibility, which is an important determinant for proactive behavior [49,52,53]. However, our mediation hypothesis regarding the connection between the existence of guidelines and innovative work behavior mediated by the flexibility of work roles received mixed support. For the dimensions idea generation and solution implementation, our results demonstrated that flexibility in work roles completely mediates the connection between the existence of guidelines and idea generation (Hypothesis 2b) and, accordingly, solution implementation (Hypothesis 2c). However, when we controlled for flexibility in a work role, the link between the existence of guidelines and knowledge acquisition remained significant, suggesting only partial mediation. This finding suggests that both direct and indirect relationships exist between the presence of guidelines and knowledge acquisition (Hypothesis 2a). We assume that in the participants' working environment, existing guidelines provide concrete details on how to acquire additional information when basic knowledge is insufficient. Therefore, knowledge acquisition may not fall as far outside healthcare professionals' existing work role as the generation and implementation of new ideas; it may thus provide an explanation for the direct effects found between the existence of guidelines and knowledge acquisition. Several studies find the breadth of knowledge sources utilized to be associated with innovativeness [e.g., 62,63] but not to be part of it. Knowledge acquisition, if interpreted to be an enabler of innovative work behavior, may be regulated by different processes than the actual idea generation

^{**} p < .01.

^{**} p < .01.

^{*} p < .05.

and implementation. The difference in results with respect to our mediation hypothesis suggests the need for further replication of the results reported here to ensure the attribution of a conceptual interpretation instead of a methodological interpretation.

Moreover, our results indicate that a high amount of variance was explained by the control variables. It is remarkable that the influence of healthcare professional expertise varied among the three dimensions of innovative work behavior. Physicians were more willing to acquire knowledge than other personnel, including nurses and therapists. However, the effects of expertise were found to be negative and significant in the models for idea generation. Thus, nurses and therapists, among others, demonstrated greater initiative for new idea generation than did physicians. This finding confirmed the insights we gained from the patient interviews we conducted in a pre-phase of this study. In those interviews, patients reported a strong commitment of out-patient nurses and therapists to identify individualized solutions. In contrast, physicians sometimes refuse to treat patients with rare diseases, "usually due to the reluctance [...] to treat them because of the complexity of their disease" [1]. Physicians in particular must invest large quantities of time in acquiring complex knowledge (which is often not part of their medical education) to treat patients with rare diseases, to provide them with adequate referrals to other healthcare services and, in the best-case scenario, to instruct other healthcare professionals. Hence, physicians are more active in the first phase of innovative work behavior, nurses and therapists, etc. in the second phase, and both equally in the implementation phase. It would be interesting to investigate whether healthcare professionals who collaborate with multi-disciplinary and cross-hierarchical colleagues implement a greater number of ideas than others because of the potential variety of positions (implying differences in their freedom to operate and in their closeness to patients), scientific knowledge and practical know-how. Furthermore, the healthcare professionals' experience in treating the given rare disease had a strong. positive influence on the first two dimensions of innovative work behavior: knowledge acquisition and idea generation. In terms of implementing new solutions, we did not find any difference according to area of specialization. However, younger healthcare professionals reported more self-realized solutions than older ones. One might argue that younger employees with fresh perspectives and limited obligations to particular organizational constituencies may be more likely to implement new ideas than older employees [64].

The array of our results supported our theoretical approach in measuring innovative work behavior according to three criteria, in contrast to the single construct used by previous studies [65]. However, the present study has limitations that should be taken into account when interpreting the findings. First, we used a cross-sectional design to test our hypotheses; thus, no inference can be made regarding causality. Although we grounded our model in existing theory, we suggest a longitudinal study design so that additional empirical evidence can be obtained to examine issues of reverse and reciprocal causality. With

respect to the limitations of a single-country study, we suggest that future studies include a broader international sample to ensure the comparability of results and to dissociate the findings from country-specific confounding variables, e.g., country-linked differences in healthcare systems or medical education. The strength of our study was our novel introduction of the flexible role ownership concept to healthcare research. In the exploratory analyses within our pre-study, the statement "it's not my job" was recurrent in care and treatment processes involving rare diseases; at the same time, this statement anchored our development of the concept of flexible role ownership [48]. To implement this fitting concept in our study, we had to adapt the items from a manufacturing context to the healthcare context. We assured the transferability of the concept using expert interviews and checked the adapted items for reasonability. In this study, we examined only possible structural influence factors on flexible role ownership. For further research, we suggest a multi-level design to simultaneously evaluate organizational, contextual and individual differences regarding the antecedents of flexible role orientation. In a manufacturing context, Parker et al. [49] suggest the recruitment of personnel with a proactive personality and changes in organizational practices to enhance job autonomy and colleagues' trust. Those factors are equally applicable to future workplace arrangements designed to foster the innovative treatment of rare diseases. The same is true of the individual-organizational connection, such as the perceived organizational support for innovation.

6. Conclusion

In practical terms, our findings suggest that if healthcare professionals are to be encouraged to seek innovative work behavior, it is beneficial to promote their flexible role orientation. For healthcare policy-makers, it is important to understand that enabling flexible role orientation may require establishing guiding principles to decrease uncertainty. Unfortunately, due to the high number of disease patterns, it is impractical to develop tailored-made guidelines for each disease. Overall guidelines are needed to facilitate and guide the care and treatment of rare diseases in general. When healthcare professionals diagnose or treat patients with rare diseases, they require guidance in how to obtain relevant knowledge. Institutions such as Orphanet (www.orphan.net) distribute existing knowledge at a multi-country (European Union) level and should thus be integrated in the process of establishing treatment guidelines for rare diseases. These guiding principles might be formulated as a code of conduct urging healthcare workers to seek greater awareness and to be open to new care and treatment processes, particularly in the case of rare diseases. It is of vital importance to encourage healthcare professionals to be flexible in adopting additional work roles, to help them to coordinate their work within the care team to avoid duplicate responsibilities and to establish cooperation between healthcare professionals and specialized centers of expertise. Due to time and financial constraints, it would be beneficial to support healthcare professionals in following the code of conduct. The provision of health services greatly depends on healthcare professionals' motivation [14,66]. Professionals can be incentivized through financial compensation for the additional efforts rare diseases require or through non-financial incentives, such as enhanced autonomy in fulfilling additional responsibilities. This arrangement may particularly empower nurses and therapists, who are often occupied within daily care and treatment processes. The nurses and therapists may become involved in generating solutions regarding care and treatment concepts, adequate technical aids or social services. Prior research indicates that empowering nurses leads to increases in innovative behavior [20,67]. This may be of the particularly high importance of nurses in implementing new solutions stage for patients, because at that stage, coordination and mutual adjustment with other healthcare professionals is needed. It is crucial to strengthen communication processes between all parties involved, regardless of their position. Communication permits all healthcare professionals to feel responsible for displaying innovative behavior at each stage to improve patients' long-term care. It also allows each healthcare professional provider to share the limited knowledge he gains while working with patients with rare diseases.

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Appendix. Scales used in the questionnaire

Existence of guidelines

Form1: Written procedures and guidelines are available for most work situations.

Form2: Formal communication channels have been established.

Form3: Written documents, such as budgets, plans, and schedules, are an integral part of the job.

Form4: Performance appraisals in our organization are based on written performance standards.

Form5: Duties, authority, and accountability of personnel are documented in policies, procedures, or job descriptions.

Flexible role ownership

Do you feel responsible if. . .

FRO1: orders for healthcare services you deal with were repeatedly not being met on time?

FRO2: patients you deal with were dissatisfied with the care they receive?

FRO3: the quality of the healthcare service in your work area was not as good as it could be?

FRO4: there was much unfinished work sitting in your area?

FRO5: there was a pile of completed work in your area?

FRO6: the way some things were done in your work area meant that additional work was needed?

FRO7: others in your work area were not pulling their weight? FRO8: people in your work area were not coordinating their efforts?

FRO9: there was a lack of well-trained people in your work area? (Eliminated due to poor factor loadings)

Knowledge acquisition

Which information sources do you consult to acquire information about the disease?

Publications, Internet, Medical databases, Formal communication rounds, e.g., Quality circles, Informal communication with colleagues and knowledge exchange with colleagues, Conferences, Additional trainings, Communication with patients, Daily work experiences.

Idea generation

IG1: I suggest new ways to achieve goals or objectives.

IG2: I come up with new and practical ideas to improve performance.

IG3: I am a good source of creative ideas.

Solution implementation

Sl1: How many ideas for the refinement of care and treatment processes in the context of disease XY did you develop in the last 24 months? (Introduction question)

SI2: How many of those ideas did you implement in your own working processes?

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